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ABSTRACT

This report describes the nation's progress in advancing public policies to increase the inclusion, empowerment, and independence of people with disabilities of all ages consistent with the vision of the Americans with Disabilities Act of 1990. The report covers the period of November 1, 1998 through November 19, 1999. It reviews federal policy activities by major issue areas, noting progress where it has occurred and making further recommendations where necessary. Progress is evaluated in the following areas: (1) disability research; (2) civil rights; (3) education; (4) health care; (5) long-term services and supports; (6) youth; (7) immigrants and racial and ethnic minorities with disabilities; (8) social security work incentives and programs; (9) employment; (10) welfare-to-work; (11) housing; (12) transportation; (13) technology and telecommunications; and (14) international issues. The report concludes that current public policy results in an unemployment rate for people with disabilities exceeding 70 percent; that current policy favors institutional placements and segregated housing over independent living with appropriate support services; and that students with disabilities are not receiving special education in regular education environments. It urges solid leadership and commitment by enforcement agencies, as well as adequate investment to enforce civil rights laws, and the enactment of a strong Patient's Bill of Rights. (CR)

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National Disability Policy: A Progress Report

November 1, 1998–November 19, 1999

National Council on Disability

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National Disability Policy: A Progress Report, November 1, 1998–November 19, 1999

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NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

LETTER OF TRANSMITTAL

May 15, 2000

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit NCD's *National Disability Policy: A Progress Report,* as required by Section 401 (b)(1) of the Rehabilitation Act of 1973, as amended. The report uses as benchmarks the recommendations for change made by disability leaders from throughout the country and captured in the 1996 NCD document *Achieving Independence.* These recommendations—elaborated upon in the ensuing annual Progress Reports—reflect a wide array of public policy areas designed to advance inclusion, empowerment, and independence of people with disabilities of all ages from diverse backgrounds consistent with the vision of the Americans with Disabilities Act of 1990 (ADA).

The attached report covers the period November 1, 1998, through November 19, 1999, the end of the 1st Session of the 106th Congress. It reviews federal policy activities by major issue areas, noting progress where it has occurred and making further recommendations where necessary. The recommendations apply to the executive and legislative branches of the Federal Government and in some instances apply to both.

NCD believes that Americans with disabilities have witnessed incremental expansion of self-sufficiency and inclusion this past year. However, far too much of our time is spent in sustaining the bedrock civil and human rights protections of the past 30 years against attempts to weaken laws such as ADA and the Individuals with Disabilities Education Act. The change in responsibility for the development of policy and program implementation from the Federal Government to state government offers opportunities for innovation. At the same time it adds tension and complexities to policy for people with disabilities who rely on such programs as Social Security benefits, vocational rehabilitation, Medicaid, Medicare, special education, and workforce development.

Thank you for the opportunity to play the independent role that our mission requires and to offer this objective assessment of progress in the past 12 months. We hope these recommendations will serve you well in the remaining months of your Administration and as we prepare to celebrate the tenth anniversary of ADA.

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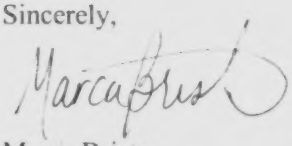
We also call on you to work with leaders in Congress and the next Administration to forge a disability agenda that brings children and adults with disabilities into the mainstream of American life.

NCD stands ready to work with you and stakeholders inside and outside the government to see that the public policy agenda set out in the attached report, in *Achieving Independence*, and in other NCD reports is implemented.

Sincerely,



Marca Bristo
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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EXECUTIVE SUMMARY

In 1999, public policy results in an unemployment rate for people with disabilities exceeding 70 percent. Public policy and expenditures give priority to institutional placements and segregated housing over independent living with appropriate support services. For households including youth with disabilities, 68 percent of the households had incomes of less than $25,000, while in the general population—households with nondisabled youth—only 18 percent had incomes of less than $25,000. A majority of the nation's 6 million students with disabilities are not receiving special education and related services in regular education environments. State and local governments are challenging the constitutionality of civil rights under the Americans with Disabilities Act (ADA).

Future public policy affecting health care, work, transportation, technology, and all other aspects of the lives of all Americans must be directed by the principles of inclusion, independent living, economic self-sufficiency, and civil rights protections in law that are protections in fact. The third edition of *National Disability Policy: A Progress Report* by the National Council on Disability (NCD) identifies the painfully incremental public policy changes that occurred in the past year that support these principles.

On December 17, 1999, President Clinton signed the Work Incentives Improvement Act (WIIA), the last act to become law in the millennium. This legislation gives people with disabilities the opportunity to move into employment and reduce their dependence on benefits and other assistance. The WIIA improves access to health care by (1) expanding states' ability to provide a Medicaid buy-in to people with disabilities who return to work; and (2) extending Medicare coverage for people with disabilities who return to work. The WIIA also attempts to improve access to health care by creating a new Medicaid buy-in demonstration to help people with a specific physical or mental impairment that is not severe enough to qualify for health assistance, but is likely to lead to a severe disability in the absence of medical treatment.

In addition, the WIIA will modernize the employment services system by creating a "ticket to work and self-sufficiency" that will enable Supplemental Security Income or Social Security Disability Insurance beneficiaries to go to any public or private provider for vocational rehabilitation.

The Federal Communications Commission issued final rules for implementation of Section 255 of the Telecommunications Act of 1996 that require manufacturers of telecommunications equipment and providers of services to address the needs of persons with disabilities as they design, develop, and fabricate their products and services. It allows individuals with disabilities to be a part of the technology revolution driving economic growth in the next century.

With the relentless oversight of NCD, the Department of Transportation (DOT) issued a final rule that ensures over-the-road bus service for passengers with disabilities. An agreement between the Department of Justice and Greyhound Lines, Inc., brings the largest provider of such services into compliance with DOT regulations. An NCD report on inadequate enforcement of the Air Carriers Access Act (ACAA) brought new DOT regulations eliminating caps for damage to wheelchairs and other assistive devices and allowing individuals to recover burdensome repair or replacement costs if their wheelchairs are lost or damaged in flight. DOT also charged Continental Airlines with violating the ACAA.

Final regulations for the Individuals with Disabilities Education Act, as reauthorized in 1997, were issued and became effective on May 11, 1999.

Important disability policy issues remain unresolved. Solid leadership and commitment by enforcement agencies, as well as adequate investment to enforce our civil rights laws, are needed to help make sure that protections in law are protections in fact. This is directed to the enforcement responsibilities of the Equal Employment Opportunity Commission and the Department of Justice on ADA and Title V of the Rehabilitation Act, the Department of Housing

and Urban Development on fair and nonsegregated housing, and the Department of Transportation on various transportation access laws.

A strong Patients' Bill of Rights must be enacted. Legislation must be enacted to allow people with disabilities to have a real choice about where they receive certain types of Medicaid long-term services and supports. Also high on the reform agenda are the Social Security and Medicare programs, both critical programs to people with disabilities and both threatened with long-term financing problems.

One of the fundamental civil rights of Americans is exercising the right to vote for their representatives and leaders at all levels of government. The year 2000 represents a critical year in which a new President will be chosen, as well as the membership and subsequent leadership of Congress. Candidates for these offices are encouraged to establish their agendas to include individuals with disabilities, with policies supporting the bipartisan principles of inclusion, independent living, economic self-sufficiency, and civil rights protections in law that are protections in fact.

PUBLIC POLICY 2000 PLATFORM: SPIRIT OF ADA FEDERAL DISABILITY POLICY FOR POLICYMAKERS AND LEADERS

The Public Policy 2000 Platform is a nonexhaustive set of statements to inform the policy visions of potential new leaders in Washington, DC, and across the country. Individuals with disabilities, advocates, and parents are looking for vision and platform statements from potential Presidential and congressional leaders that advance the independence, full participation, and productivity of people with disabilities. In exercising one of the fundamental rights in a democratic society—voting—these Americans are looking for specifics on how we:

Enforce human and civil rights laws protecting individuals with disabilities, including the Americans with Disabilities Act, the Individuals with Disabilities Education Act, Title V of the amended Vocational Rehabilitation Act, the Fair Housing Act, Section 255 of the Technology Act, and the Air Carriers Access Act.

- Preserve and enforce the federal commitment to quality education for all children, including children with disabilities.

- Establish a system of health care that supports individualized care needs of people with disabilities, continued work opportunities, prevention of secondary conditions, and long-term care supports that allow individuals to live in their homes or in the least restrictive environment.

- Create a continually improving accessible environment in physical structures and pathways, transportation, and technology utilizing the concepts of universal design.

- Ensure that generic education, health, workforce development, housing, and other

programs in which authority for development of service systems has been substantially returned to the states serve individuals with disabilities.

- Ensure a secure funding base for existing programs serving individuals with disabilities through the next decade under the goals and spending limits of the Balanced Budget Act of 1998.

- Identify the key factors that need to be addressed to significantly reduce the 75 percent unemployment rate of individuals with disabilities.

- Take national and international steps to ensure access to technology and participation in the global technological economy.

- Establish a foreign policy that supports the goals of access, civil and human rights, inclusion, and poverty reduction of individuals with disabilities throughout the world.

In the new century, America will realize even more of its promise because we have unleashed the promise of more Americans.

—President William Clinton, at the signing of the Work Incentives Improvement Act of 1999.

INTRODUCTION

The most significant legislative achievement for people with disabilities of the past year was the milestone passage of the Work Incentives Improvement Act of 1999. Enactment of this employment initiative will facilitate and catalyze the spirit of equality, justice, and opportunity embodied in the Americans with Disabilities Act (ADA). At the signing ceremony on the site of the FDR Memorial, President Clinton said:

> *Clearly, this is the most significant advancement for people with disabilities since the Americans with Disabilities Act almost a decade ago. It continues our administration's efforts to replace barriers to opportunity with policies based on inclusion, empowerment and independence.*

The efforts of several years and sessions of Congress came to fruition when some of the major, ongoing barriers to work were addressed in the legislation. Having captured the attention of people with disabilities, their families, and advocates across the country, a bipartisan, bicameral effort was fueled by the hard work of disability advocates and the bills' chief sponsors and their staffs. Designed to enhance the employment of people with disabilities, this law has five major features: health insurance improvements—at the option of states; ticket-to-work and self-sufficiency; work incentive enhancements; new work incentive service structure; and a work incentive demonstration authority.

WIIA, along with the Workforce Investment Act of 1998, can be models for the new millennium of customer-focused, multi-agency partnerships to revamp public and private systems that help people achieve gainful, competitive employment. Most prominent among the barriers to employment that the Act removes is the disincentive to work caused by inconsistent national policies; for example, if a person with a disability *gains* employment she *loses* health and other benefits. This legislation will enable individuals with disabilities to go to work without losing their eligibility for Medicare and Medicaid. However, states have a choice whether or not to participate in this elective program. Disability advocates recognize the opportunity and responsibility to promote the benefits of the law's provisions and ensure that states elect to participate and successfully implement the Act. The Presidential Task Force for the Employment of Adults with Disabilities "push(ed) forward the message to all stakeholders, including the Administration, Congress, Governors, State and local officials, people with disabilities, employers, and other interested parties: The Time for Action is Now." The Task Force's second report to the President laid out an ambitious set of recommendations to increase the employment rate of people with disabilities. Recognizing that the era of isolation and specialized services is over, the Task Force promoted progressive changes in generic employment and training systems and supported various departmental initiatives to build the capacity of these agencies to serve people with disabilities successfully.

The Federal Communications Commission put rules and policies for implementation of Section 255 of the Telecommunications Act of 1996 into place with the issuance of final regulations. The statute and the regulations require manufacturers of telecommunications equipment and providers of services to address the needs of persons with disabilities as they design, develop, and fabricate their products and services. It allows individuals with disabilities to be a part of the technology revolution driving economic growth in the next century.

Increased funding for civil rights enforcement proved beneficial in lowering the backlog of complaints at the major enforcement agencies, the Equal Employment Opportunity Commission,

and the Department of Justice, as well as in finding new enforcement strategies against discrimination toward individual with disabilities.

Final regulations for the Individuals with Disabilities Education Act, as reauthorized in 1997, were issued and became effective on May 11, 1999.

Transportation policy supporting individuals with disabilities included the April 1, 1999, publication of a final rule that ensures over-the-road bus service for passengers with disabilities as well as an agreement between the Department of Justice and Greyhound Lines, Inc., which will bring the nemesis of the disability community into compliance with Department of Transportation (DOT) regulations. Current DOT regulations permit carrying riders, but require Greyhound to provide life-equipped bus service on 48 hours' notice beginning in October 2001. Funds from the Federal Transit Authority are being made available for training and incremental capital costs in making over-the-road buses wheelchair-accessible.

Partially in response to a National Council on Disability (NCD) report on inadequate enforcement of the Air Carriers Access Act (ACAA), DOT issued new regulations eliminating caps for damage to wheelchairs and other assistive devices by allowing individuals to recover burdensome repair or replacement costs if their wheelchairs are lost or damaged in flight. DOT also charged Continental Airlines with violating ACAA.

While these victories represent a persistent, but hauntingly slow, pace for disability policy, several issues covered in all our Progress Reports remain unresolved. Health care initiatives—that now have broad-based bipartisan support—must receive action during the Second Session of the 106th Congress. A strong Patients' Bill of Rights must be enacted.

On November 16, 1999, the Medicaid Community Assistance Services and Supports Act was introduced in the Senate as bill number S. 1935, co-sponsored by Senators Tom Harkin (D-Iowa) and Arlen Specter (R-Pennsylvania). The bill allows people with disabilities to have a real

choice about where they receive certain types of Medicaid long-term services and supports. It also provides grants to the States to assist them as they redirect Medicaid resources into community-based services and supports. Supported by the U.S. Supreme Court decision in *Olmstead v. L.C.*, NCD calls for the nationwide reform of long-term care services in the least restrictive environment that this legislation provides.

Other important health care initiatives include medical records privacy protections, health care options further empowering Americans with disabilities to work free from concern of being uninsured, increased funds for children's health insurance outreach, and support services and coverage of legal immigrants.

Also high on the reform agenda are the Social Security and Medicare programs, both critical programs to people with disabilities and both threatened with long-term financing problems. Increasingly, advocacy groups of and for people with disabilities are participating in the ongoing discussions, a trend NCD is pleased to witness.

At the dawn of a new millennium, many Americans are re-evaluating how they live, learn, work, and play. It is a natural time to question whether the systems that comprise America's public and private service provision are characterized by policies, programs, products, and practices that empower and include all Americans. During the second half of the past century, developments in public policy led to unprecedented statutory affirmation of the civil rights of people with disabilities, raising expectations of access, inclusion, and participation in the mainstream of American society. NCD believes that now is the time to transform systems to make good on the promise.

This report, which updates the Progress Report issued by NCD in 1998, will describe significant policy developments in the past year and offer recommendations for the President and the Members of the 106th Congress of the United States of America.

PROGRESS, CONCERNS, AND RECOMMENDATIONS

A. DISABILITY DEMOGRAPHICS AND DISABILITY RESEARCH

1. Census 2000

In *Achieving Independence,* the National Council on Disability (NCD) recommended that all federal statistical activities that include data collection and reporting for other groups, such as minorities and women, include the category of people with disabilities, using definitions based on the Americans with Disabilities Act (ADA). Based on in-depth results of a multi-agency working group, which included the Census Bureau, recommendations were made to Congress to include a new disability question set in Census 2000. Questions are now integrated into Census 2000. This milestone accomplishment will yield critical information. Twenty percent of Americans have some type of disability and about 10 percent have a severe disability. The law requires the Census Bureau to ask about disability; the resulting statistical information supports programs that help people with disabilities. The 2000 Census will ask three questions in the long form, sent to one in every six households. When populations are sparse, in rural areas or are residing on reservation land, the frequency of surveys may increase. The three questions cover general areas of defining disability, age, and ability to function with a limitation:

1. The kind of disability and its limitation on essential function of daily living;

2. The limitation to work resulting from disability; and

3. The age whether over 16 in the year 2000 or under 15 in the year 2000 and the limitation the disability may effect on mobility/independence.[1]

NCD emphasizes the importance of individuals with disabilities participating in Census 2000, when the nation will count the general population and include disability issues as a critical aspect of American demographics.

2. Demographics

The National Institute on Disability and Rehabilitation Research (NIDRR) at the Department of Education (DOED) has published an extensive *Chartbook on Work and Disability in the United States in 1998*. Both NIDRR and the Social Security Administration published *The Summary of Data on Young People with Disabilities* in 1999. These two sources draw on data from sources such as the National Health Interview Survey, the National Center for Education Statistics, the Current Population Survey, and the Survey of Income and Program Participation.

Summary Data Highlights

- Among the 25.1 million people 15 to 21 years of age, 12.1 percent have a disability, and 3.2 percent have a severe disability.

- The head of household's educational attainment was significantly lower for youth with disabilities. Parents or guardians who had not completed high school were heads of household for 41 percent of youth with disabilities. By comparison, the heads of households who had not completed high school for youth ages 12 to 17 in the general population was 22 percent.

- Typical household income for youth with disabilities was considerably lower than for youth in the general population. For 35 percent of the youth with disabilities, household income was less than $12,500, compared with the general population of

youth age 12 to 17, where 18 percent of the households had incomes of less than $12,500. For households including youth with disabilities, 68 percent of the households had incomes of less than $25,000, while in the general population, households with nondisabled youth, only 18 percent had incomes of less than $25,000.

- In 1987, about half of all youth with disabilities lived in households that were receiving benefits from at least one public source. Food Stamps comprised 24 percent, and Medicaid or other state-supported health benefits comprised 22 percent.

The Chartbook on Work and Disability in the United States, 1998 reported the following:

- 32.1 million working age people, ages 15-64, have a disability. Of these, severe disabilities were reported by 14.9 million (8.7 percent).

- In the age group 18 to 69 years old, statistics by race and ethnic origin were as follows:

Ethnic Group	**% Work Limitation**	**% Unable to Work**
Native American	17.3	10.4
Black Hispanic	15.9	13.2
Black (non-Hispanic)	14.3	10.3
White (non-Hispanic)	11.6	6.2
White Hispanic	9.5	6.3
Asian/Pacific Islander	5.7	3.4

- *The Chartbook* reports substantially lower monthly earnings income for working people with disabilities as compared to the working nondisabled :

	Median Monthly Earnings	
	Men	**Women**
Severe Disability	$1,262	$1,000
Nonsevere Disability	$1, 857	$1,200
No Disability	$2,190	$1,470

3. Research Challenges and Recommendations

The challenge ahead is for data and research to meet the decisionmaking needs of policymakers. In data collection and research, what the person with a disability experiences within the environment is an important perspective. The context of one's life determines the success of choice and integration.

NCD recommends that the federal research community emphasize cross-cultural studies and the experiences the environment presents to people with disabilities in all age brackets. NCD recommends that the Interagency Committee on Disability Research, required by the reauthorized Rehabilitation Act, be provided with adequate resources.

B. CIVIL RIGHTS

"We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain inalienable rights." The United States Congress and the President

have recognized the fundamental rights of people with disabilities to make choices, pursue meaningful careers, live independently, and participate fully in all aspects of society.

—President George Bush, at the signing of the Americans with Disabilities Act into law, July 26, 1990.

Overseeing civil rights protection of individuals with disabilities is a vital responsibility of NCD. The 1996 *Achieving Independence* report overwhelmingly set improved enforcement of civil rights protections within its top priorities. In response, NCD established the "Unequal Protection Under the Law" series. The multiple-year series provides independent analyses of the federal enforcement of existing civil rights laws, including ADA, Section 504 of the Rehabilitation Act, the Individuals with Disabilities Education Act (IDEA), the Fair Housing Amendments Act, and the Air Carriers Access Act (ACAA). During the period of this progress report, NCD released its first statute-specific analysis of the ACAA (March 1999). This report will be discussed in the transportation section of this report.

The following section of the report, along with the education, technology, and transportation sections, includes NCD's analysis of specific developments in civil rights law, the courts' construction of that law, and policy during the covered period. *It also reviews enforcement of existing civil rights statutes for individuals with disabilities by the primary enforcement agencies with those responsibilities. No American in the 21st century should have to face discrimination when it comes to finding a home, getting a job, going to school, or securing a loan. Solid leadership and commitment by enforcement agencies, as well as adequate investment to enforce our civil rights laws, are needed to help make sure that protections in law are protections in fact.*

Agencies with primary enforcement responsibilities for civil rights for individuals with disabilities include:

- Department of Justice, Civil Rights Division. Adequate funding and leadership would permit the Justice Department to expand significantly investigations and prosecutions of criminal civil rights cases (including hate crimes and police misconduct), fair housing and lending cases, and the Division's enforcement of ADA.
- Equal Employment Opportunity Commission (EEOC). Major resources must be dedicated to reducing the backlog of private sector cases and improving the federal EEO complaint process for all protected classes, including individuals with disabilities.
- Department of Housing and Urban Development's (HUD) Fair Housing Initiatives. Adequate resources would support HUD's efforts to continue its review of policies needed to reduce housing discrimination against individuals with disabilities. Such resources would support the final year of a three-year, audit-based housing discrimination study being conducted in 20 communities around the country that includes specific questions on accessibility for individuals with disabilities.

But first, the report looks at the fundamental civil right necessary in a democracy: the right to vote. It also identifies the critical nature of this right in the coming election year.

1. Voter Registration and Voting

One of the fundamental civil rights of Americans is exercising the right to vote for their representatives and leaders at all levels of government. The year 2000 represents a critical year in which a new President will be chosen, as well as the membership and subsequent leadership of Congress. Other critical policy decisions and directions will be in the hands of the new President and Congress, including (1) reapportionment of congressional districts for the next decade, based upon the 2000 Census, and (2) the appointment of new Supreme Court Justices who will

determine the trend in judicial decisions for many years to come. These actions will determine how federal civil rights protections are going to be judicially decided well into our lifetimes.

Efforts to improve the access of individuals with disabilities to the entire voting process have been enacted in the past two decades. Public Law 103-31, the National Voter Registration Act (NVRA), established a national voter registration procedure for federal elections that permits quick, convenient registration at motor vehicle and other state agencies. It was the intent of Congress to specifically encourage voting by people with disabilities who traditionally have been left out of voter registration activities. Section 7(a)(2)(B) of this Act requires each state to designate agencies for registration of voters including "offices...that provide services to persons with disabilities."

A review by NCD of the implementation of NVRA by state vocational rehabilitation agencies, who serve as many as 650,000 new individuals with disabilities a year, found that implementation of this law by states is inconsistent and poorly coordinated. Significant differences in agency attitude toward proactively implementing the Act were found. This included the level of commitment and practices in advising individuals of their opportunity to register to vote, training staff on their work responsibilities under NVRA, and assigning NVRA management and performance oversight among staff at all levels of the agency. The NCD report offers recommendations that have been successfully enacted in agencies (http://www.ncd.gov/newsroom/publications/voter.html).

NCD encourages all public disability service agencies, including special education agencies, to vigorously offer this public service to ensure that registering and voting are made easier for individuals with disabilities. NCD encourages bipartisan national, state, and local voter registration and get-out-the-vote initiatives for individuals with disabilities and their families and advocates. NCD reiterates its challenge to the President and Congress to enact legislation amending the 1984 Voting Accessibility for the Elderly and Handicapped Act. Such amendments would include the recognition of the right of all individuals to vote independently, guaranteed

accessibility to all stages of the electoral process (from voter registration to election-day practices), and meaningful technical assistance and enforcement mechanisms to ensure the right to vote.

2. Supreme Court Rules on a Significant Number of ADA Cases

The U.S. Supreme Court continued its hearing of cases interpreting ADA, beginning in the first year of the 1998-1999 term. Overall, concerns raised in several Supreme Court decisions, caution must be exercised in interpreting these new rulings, which represent mixed results for the civil rights of individuals with disabilities. To realize the promise of ADA, disability legal advocates and the community must also follow the rulings with vigorous new strategies.

Olmstead v. L.C.

The Supreme Court issued a watershed opinion regarding the proper construction of the anti-discrimination provision contained in the public service portion (Title II) of the ADA in *Olmstead v. L.C.* (138 F.3d.893.119 S. Ct. 633). The Court specifically confronted the question of whether the proscription of discrimination may require placement of individuals with mental disabilities in community settings rather than in institutions. The Court answered the question with a qualified yes.

For the disability community, the Supreme Court's opinion in *Olmstead v. L.C.* represents a victory with strings attached. The *L.C.* opinion is the most significant ADA decision acknowledging that unjustified isolation is a form of discrimination under the ADA's integration mandate. The *L.C.* decision expands options for individuals who are currently in state mental institutions because it affirms a right for an individual to receive community-based services. As the Court noted: "Institutional placement of persons who can handle and benefit from

community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life and cultural enrichment."

The Court further stressed that confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

However, the Court also ruled that this action hinges on whether the "state's treatment professionals have determined that community placement is appropriate, the transfer from the institutional care to a less restrictive setting is not opposed by the affected individuals, and placement can be reasonably accommodated, taking into account the resources available to the state and needs of others with mental disabilities."

NCD commends the court in its determination that unjustified isolation is properly regarded as discrimination when it is based on disability. The Department of Health and Human Services is commended for its letter to state Medicaid Directors and others emphasizing the Court's suggestion that a state could establish compliance with Title II of ADA if it demonstrates that it has (1) a comprehensive plan for placing qualified individuals with disabilities in less restrictive settings, and (2) a waiting list that moves at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated.

NCD recommends that states involve institutionalized individuals with disabilities in the development of the comprehensive plan with key principles and practices that should be considered. These principles and practices would address issues such as rendering criteria for community placement, lessening the subjectivity of treatment officials, and the chances of state funding allocations taking precedence over individualized planning. Clarification is needed of what resources must be considered by the state as causing an inequitable burden, as well as many other issues.

Sutton v. United Airlines*, *Albertsons Inc. v. Kirkingburg*, and *Murphy vs. United Parcel

The Supreme Court ruled on the "definition of disability" in *Sutton v. United Airlines* (130 F.3d 893, 119 S. Ct. 2139), *Albertsons Inc. v. Kirkingburg* (143 F.3d 1228, 119 S. Ct. 2162), and *Murphy vs. United Parcel* (141 F.3d 1185, 119 S. Ct. 1331), stating that ADA does not cover those persons with correctable impairments. If a person does not experience a substantial limitation in a major life activity when using a mitigating measure such as medication, glasses, or other corrective devices, then that person is not considered disabled under the law. In *Albertsons Inc.*, the Court ruled that an employer who requires an employee as part of a job qualification to meet applicable federal regulations does not have to justify enforcing those regulations, even if there is an experimental waiver program. These rulings unfortunately restrict coverage for people with epilepsy, diabetes, and other serious long-term impairments.

The three cases involved people with poor uncorrected vision, monocular vision, and hypertension who were challenging discriminatory employer policies that unfairly excluded them based on their impairments. *NCD believes that, in deciding that these people fall outside the civil rights protections of ADA because their conditions are correctable, our highest court has left many people with treatable conditions such as epilepsy, diabetes, and bipolar disorder outside the law's protection as well. Anyone who is functioning well with their disability is now at risk of losing civil rights protections as a result of the Supreme Court's "miserly" construction, to use Justice Stevens' characterization in his eloquent dissent.*

One of the core findings in ADA is that "disability is a natural part of the human experience." This is a powerful statement. "Disability" should not be interpreted by the Supreme Court to exclude the many people whose conditions in their natural state result in significant impairments in functioning but who can function well with medication, assistive devices, or other mitigating measures. The people who would be left out nonetheless will continue to encounter bigotry and attitudinal barriers when they are turned down for jobs or are passed over for promotions.

When Congress defined disability in ADA, they intentionally used the inclusive, flexible definition that has been in place for many years under the Rehabilitation Act. The ADA definition includes not just people with physical or mental impairments that substantially limit at least one major life activity, but also people with a history of such impairments, and people who are regarded by others as having such impairments.

If Congress wanted to limit coverage to people in wheelchairs, blind people, and deaf people, they certainly could have. Instead, Congress followed the advice of NCD and others and incorporated an inclusive definition of the protected class that would reach the many and varied ways that fears, myths, and stereotypes come into play to unfairly limit people based on their physical or mental conditions as opposed to their work experience and proven abilities.

Cedar Rapids School District v. Garret F.

In *Cedar Rapids School District v. Garret F.* (106 F.3d 822, 119 S. Ct. 37), the Supreme Court affirmed the right of all students with disabilities to attend school when they are medically able to do so, regardless of the nature or extent of the health-related services they may require during school hours, as long as those services are not required to be provided by a physician.

The Court held that schools are required by IDEA to provide students with nursing and/or other health-related services during the school day. *Garrett F.* provides students in need of medical services an equal opportunity to attend school alongside their peers. To the extent that in-school health services are needed, they must be provided. Thus *Garrett F.* provides children with disabilities who need in-school health-related services meaningful access to public schools

NCD encourages state governors and state attorneys general to embrace and enforce the civil rights requirements of ADA more vigorously and to seek more cost-effective ways to bring the instruments of state and local government into compliance.

Cleveland v. Policy Management Systems Corp.

In *Cleveland v. Policy Management Systems Corp.* (120 F.3d 513, 119 S. Ct. 900), the Supreme Court unanimously held that pursuit and receipt of Social Security Disability Insurance (SSDI) benefits does not automatically stop a recipient from pursuing an ADA claim or create a strong presumption against success under ADA. Key distinctions were made between ADA and SSDI claims. *NCD applauds the unanimous decision of the Court, bringing to an end the dilemma the "estoppel" issue had held for individuals being unable to pursue their civil rights while seeking the assistance they needed to live while unemployed.*

Wright v. Universal Maritime Service Corp.

Finally, the Supreme Court ruled in *Wright v. Universal Maritime Service Corp.* (121 F.3d 702, 118 S. Ct. 900) that a collective bargaining agreement general arbitration clause does not require an individual to use the arbitration procedure for alleged violation of the ADA. The individual may proceed to court with his anti-discrimination claim.

3. Hate Crimes

Federal authorities currently may prosecute violent civil rights abuses when state authorities are unable or unwilling to do so. However, federal jurisdiction is triggered only when two circumstances are present. First, the impetus for the crime must have been based upon the victim's race, national origin, or religion. Second, either the crime must have occurred while the victim was enjoying a federally protected right—such as voting or serving on a jury—or the crime must have interfered with the victim's ability to engage in a similar right.

The Hate Crimes Prevention Act of 1999, added as an amendment by the Senate to the Commerce, Justice, and State appropriations bill, would extend the present hate crimes statutes to cover disability, gender, and sexual orientation. The amendment would have allowed federal

officials to prosecute hate crimes even when the victim is not engaged in "federally protected activity." President Clinton vetoed the bill to fund the Departments of Commerce and State because, amongst other reasons, it didn't include the Hate Crime Prevention Act provisions. The final appropriations for these agencies negotiated between congressional leadership and the President did not include the hate crime protections. *NCD believes we must do more to root out forces of hate and intolerance and encourages the 106th Congress and the President to reach agreement on strong hate crime protections to those in our society who are still threatened by violence simply because of who they are.*

4. Enforcement

Equal Employment Opportunity Commission

Chair Comments on Supreme Court Decisions

EEOC chair, Ida L. Castro, has summarized the Supreme Court's decisions this past year regarding cases related to the Americans with Disabilities Act as significantly narrowing the scope of those covered under ADA. However, the decision affirms EEOC's standard of an individualized approach to the assessment of coverage under ADA. Castro stated, "(P)eople who use mitigating measures may still be substantially limited in major life activities and thus enjoy the protection of the ADA." She also noted, "the Court did not suggest that any conditions are *per se* excluded from coverage under ADA, and the Court did not disturb the principle that employers are required, as before, to provide reasonable accommodations for people with disabilities and may not otherwise discriminate against them." EEOC staff point out that the ADA still protects people with past and perceived disabilities—even if they have no current impairment at all. Many people who experience discrimination on the basis of currently controlled conditions will be protected under these prongs of the statute.

Budget Increases for Enforcement

The Omnibus Appropriation Bill passed by Congress on October 21, 1998, funded the agency at a level of $279 million, consistent with the President's Civil Rights Enforcement Initiative.

EEOC Enforcement Practices

Comprehensive Enforcement Program: During 1999, EEOC began implementing an agency-wide Comprehensive Enforcement Program (CEP) to improve all components of agency operations in both the private and federal sectors. As a result of several years of reform in management of incoming and pending complaints, the pending inventory has been slashed to a 15-year low of 40,234—a 23 percent decline from 52,011 at the close of fiscal year (FY) 1998.

EEOC resolved more cases that impact large groups of individuals. The resolution of systemic cases increased by 67 percent during FY 1999. EEOC resolved 50 such cases, compared to 30 in FY 1998. EEOC filed more lawsuits affecting multiple parties or addressing discriminatory policies. EEOC filed 112 of these suits in FY 1999 compared to 82 in FY 1998.

National Mediation Program: EEOC's National Mediation Program was launched in February 1999 and became fully operational in April 1999. By the end of FY 1999, the agency had nearly tripled the number of successful charge resolutions handled through voluntary mediations to 4,833 (up from 1,631 in FY 1998).

NCD compliments EEOC on its continued efforts toward reducing the pending inventory of private sector charges and lowering the average charge processing time. It is critical that improved complaint processing cut across all protected classes, including individuals with disabilities. ADA charges surrounding failure to hire and to provide reasonable accommodations can be subtle and complex, just as coding and other employer practices proved to be in race-based cases. Continual evaluation of the Priority Charge Handling Process and

the new CEP practices must ensure that ADA charges are proportionally among the cases determined meritorious. NCD wants to make sure the increased merit factor rate, those charges that show a favorable finding for the charging party (settlements including mediation, cause resolutions including those litigated, and charge withdrawals with benefits), represents all protected classes. Data currently show the merit factor rate for non-ADA cases as 17.4 percent, while the rate for ADA cases is 13.3 percent. NCD commends the increased use of systemic and multiple party litigation and recommends ADA-based discrimination as a part of the enforcement plan for such litigation.

ADA-Specific Conciliations and Litigation

- A $167,000 settlement in a disability discrimination suit brought under the Americans with Disabilities Act against TMC Transportation of Des Moines, Iowa, on behalf of a former TMC over-the-road truck driver. The suit alleged that TMC violated ADA by refusing to schedule the driver's runs in a way that would accommodate regularly-scheduled medical visits to treat his lupus disease, and by firing him because of the disease rather than returning him to work as a driver.
- A jury in the disability discrimination case against the Chuck E. Cheese's pizza chain returned its verdict on damages Friday, awarding a record $13 million in compensatory and punitive damages to Donald Perkle. This verdict represents the largest monetary relief awarded by a jury in a case brought by the EEOC under the ADA. The jury found that Chuck E. Cheese's violated the employment provisions of the ADA by discriminating against Mr. Perkle when they fired him because of his disability, mental retardation.

Policy Guidance and Regulations

Federal Sector Regulations: On July 12, EEOC issued new regulations (29 C.F.R. Part 1614) to improve the federal equal employment opportunity (EEO) complaint system by

eliminating unnecessary layers of review, modifying data collection, utilizing alternative dispute resolution throughout the process, and addressing perceptions of unfairness in the system.

ADA Guidance: On March 1, 1999, EEOC released comprehensive policy guidance titled "Reasonable Accommodation and Undue Hardship Under the Americans with Disabilities Act (ADA)." The guidance provides answers to the most frequently asked questions concerning what reasonable accommodations are, when they must be provided, and when employers may refuse to provide them. It points out that providing a reasonable accommodation does not mean excusing poor performance or hiring unqualified people. The guidance also represents the Commission's most complete discussion to date of "undue hardship," which is a limitation on an employer's obligation to make a reasonable accommodation.

NCD commends EEOC for instituting a series of actions to review its own documents that may need to be revised and updated. NCD wishes to work with EEOC and the new Reinventing Government initiative on federal sector civil rights complaint processing practices to ensure that the new Federal Sector Regulations adequately collect data on federal employees with disabilities and provide adequate procedural protections.

Department of Justice

ADA Penalties Adjusted for Inflation

The Department of Justice (DOJ) may file lawsuits in federal court to enforce ADA and may obtain court orders including compensatory damages and back pay to remedy discrimination. As of September 29, 1999, the limit on possible penalties has been adjusted upward for inflation to $55,000 for the first violation and $110,000 for any subsequent violation.

Circuits Split on Constitutionality of ADA Suits Against States

DOJ has made concerted interventions in U.S. Courts of Appeals and District Courts in upholding the constitutionality of ADA suits against states and localities. This has become a critical court test, likely to reach the Supreme Court during the second half of the current Court term.

Two more U.S. Courts of Appeals have upheld ADA as appropriate legislation to enforce the equal protection guarantees of the U.S. Constitution. The Second Circuit in *Muller v. Costello* (997 F. Supp. 299), an employment suit alleging discrimination against a New York State prison, and the Tenth Circuit in *Martin v. Kansas* (996 F. Supp. 1297), an employment claim against a Kansas prison, ruled that it is constitutional for Congress to permit individuals to directly sue states for ADA violations under Title I because ADA is appropriately tailored to remedy and prevent discrimination against people with disabilities.

On the other hand, the Eighth Circuit in *Alsbrook v. City of Maumelle* (184 F. 3rd 999 [8th Cir. 1999]) ruled that a Title II suit against the Arkansas Commission on Law Enforcement Standards and Training was unconstitutional because ADA's protections go beyond the equal protection rights guaranteed by the U.S. Constitution. It also ruled for the same reason in *DeBose v. Nebraska* that a Title I employment suit against Nebraska was unconstitutional. In all four of these cases the DOJ intervened to defend the constitutionality of the ADA. Seven of the eight circuits ruling on this issue so far have upheld the constitutionality of ADA suits against states. As urged by the Department, the U.S. District Court for the District of Connecticut also upheld the constitutionality of a Title II suit against the Connecticut Department of Corrections in *Hicks v. Armstrong*.

The Department sought to intervene in two additional district court cases, *Campos v. San Francisco State University N.D. Cal.*, 1999 (No. C-97-2326 MMC) and *Jeffreys v. New Jersey*, in which states are arguing that it is unconstitutional for Congress to permit ADA lawsuits

directly against state governments. California and New Jersey assert that Congress lacks authority under the Fourteenth Amendment to subject them to lawsuits under ADA, because ADA's protections go beyond the equal protection rights guaranteed by the U.S. Constitution. The Department, however, believes that ADA is constitutionally appropriate legislation to remedy the history of pervasive discrimination against people with disabilities.

NCD commends DOJ in its efforts on this constitutional issue critical to the entire meaning of ADA and Section 504 regarding the civil rights of individuals with disabilities in their relationships with state and local units of government. NCD encourages the Supreme Court, should they review this issue, to determine that Title II of ADA and Section 504 of the Rehabilitation Act constitutionally apply to state and local governments.

Furthermore, federal judges need to develop greater understanding of the principles of ADA and other disability civil rights laws. NCD recommends to the President and Congress that they work together to identify, appoint, and confirm to the federal bench qualified lawyers and judges with disabilities who have an understanding of the legal and philosophical principles of the disability civil rights movement.

Department of Housing and Urban Development

Laws such as the Fair Housing Act (FHA) are intended to end the unnecessary exclusion of persons with disabilities from the American mainstream and to provide them with the freedom to choose where they wish to live and be free of discrimination in housing. In combination with Section 504 of the Rehabilitation Act, FHA and ADA redress discrimination in housing and in community development programs.

Complaint Investigations

The Department of Housing and Urban Development's (HUD) field offices and state and local

governmental agencies that have substantially equivalent laws investigate complaints alleging discrimination based on disability under FHA. Complaints alleging discrimination on the basis of disability filed against both private and federally assisted housing providers now constitute the second highest number of complaints filed with HUD. FHA provides the same or greater remedies to victims of discrimination as Section 504, and a finding of discrimination can render a HUD recipient of funding ineligible for future HUD funding. HUD's policy is that, any time a Title VIII complaint is filed against a recipient of HUD funds, that complaint also is filed under Section 504 as well as the ADA, if the latter applies.

From October 1, 1989, to the close of FY 1998, 2,791 discrimination complaints alleging discrimination under Title VIII and Section 504 and/or ADA were filed with HUD. Of those complaints, HUD successfully conciliated 1,224. A determination of reasonable cause was made in 43 HUD cases. These figures do not include the relatively small number of complaints filed against HUD recipients [?] that allege disability discrimination in employment or a program unrelated to housing, which would be filed only under Section 504 or ADA. During the past five years, there has been a 68 percent increase in the total number of Section 504 cases filed with HUD compared with the previous five years.

Sections 810(f) and 817 of the FHA authorize referral of fair housing complaints to state and local agencies certified to provide substantially the same rights, procedures, remedies, and judicial review as are found in the FHA and to reimburse those certified agencies for effectively processing complaints referred to them. Certified agencies received federal and technical assistance through the Fair Housing Assistance Program (FHAP).

From FY 1991 to FY 1998, a total of 6,016 complaints that alleged housing discrimination based on disability were filed with FHAP agencies under Title VIII. Of those complaints, 96 resulted in cause-type determinations. The number of disability complaints filed with FHAP agencies during the latter half of this eight-year period is more than double the number filed during the previous four years. FHAP agencies conciliated 2,263 cases during the eight-year period and,

likewise, conciliated twice the number of cases during the second four years than were conciliated during the first four years. These FHAP conciliations obtained 534 housing units (a 200 percent increase over the first four years) and $3.9 million in relief to complainants (a 767 percent increase over the first four years).

Even though conciliations increased for FHAP agencies during this period, these statistics also point out the concerns of disability housing advocates. Accounting for cause-type determinations and conciliations, 51 percent of the complaints made to HUD and 54 percent of the complaints filed with FHAP agencies remain unresolved or nearly half have been closed without cause. Based upon previous court decisions, HUD developed a guide for all investigators to use in FHA and Section 504 disability fair housing discrimination complaints. A review of the guide by the Disability Rights Action Coalition for Housing and advocates pointed out inquiries to the nature and severity of an individual's disability and other factors unnecessary to the determination of a person's eligibility for fair housing protection and not ancillary to the facts surrounding the complaint. As a result of discussions with advocates, the HUD Office of Fair Housing and Equal Opportunity (FHEO) has agreed to modifications to the guide questionnaire focusing on the actions of the parties identified in the discrimination complaint.

NCD continues to recommend that HUD use consecutive fiscal year increases in appropriations for fair housing to expand its enforcement of the Fair Housing Act and Section 504 of the Rehabilitation Act on behalf of people with disabilities. To the extent that HUD continues its commitment to doubling enforcement efforts under the Fair Housing Act, NCD recommends that HUD's efforts under section 504 also be doubled. This goal has not been met. The changes in the FHEO guide and questionnaire for Fair Housing Analysts to conduct these enforcement activities are commended.

Through the Real Estate Assessment Center, which reports to the Secretary, HUD continues a three-year systematic review of the physical plants of HUD-financed projects to assess compliance with many different safety and conservation standards. Also being surveyed are all

newly constructed multifamily housing (with four or more contiguous units) built since March 1991 (the effective date of the Fair Housing Act's new construction guidelines). As part of this effort, HUD inspectors are assessing compliance with accessibility laws and regulations, such as section 504 of the Rehabilitation Act. Four items are being assessed:

- Is there an accessible route to and from the main floor entrances of buildings inspected (e.g., a level surface to the door and, if there are stairs, a ramp)?
- Is the main entrance for every building inspected at least 32 inches wide, measured from between the face of the open door and the opposite door jamb?
- Are there accessible routes to all exterior common use areas (e.g., curb cuts, stairs, ramps, lever-type door handles, pathways at least 36 inches wide)?
- For multi-story buildings, are the interior hallways to all units and common areas at least 36 inches wide?

While these questions will not determine whether full access exists, the answers will provide statistically reliable information on the numbers, types, and locations of buildings that do and do not comply with even the basics of the Fair Housing Act. Initial sample survey results have been collected by the Real Estate Assessment Center, but the process for release of the data through FHEO or HUD's Division of Policy Development and Research has not been established. *NCD strongly encourages HUD to make the results of this survey public at statistically valid periods throughout the data collection activities. This information could be invaluable in supporting appropriate funding for Mainstream Tenant Based Rental Assistance (TBRA) and the TBRA authorities of the 811 program. It will assist in the development of State Consolidated Plans and local "Public Housing Authority Plans" that adequately address the housing needs of individuals with disabilities.*

In March, U.S. Department of Agriculture (USDA) rural Housing Programs representatives opened discussions with advocates regarding fair housing and civil rights for individuals with

disabilities in rural USDA-funded rental and home ownership programs. *NCD commends USDA in this effort.*

Civil Rights Needs of Psychiatric Survivors

A. NCD Albany Conference on Civil Rights for Psychiatric Survivors

NCD conducted a hearing in Albany, New York, in November 1998, to learn more about the problems of psychiatric disability. Psychiatric survivors are routinely deprived of their rights in a way no other disability group has been. At the hearing, NCD heard testimony from mental health professionals, lawyers, advocates, and relatives of psychiatric survivors. However, unlike most investigations on the topic of psychiatric disability, the primary participants in this hearing were psychiatric survivors themselves, who testified passionately and eloquently both about the mistreatment they had experienced or witnessed and their proposals for real and viable change. NCD heard testimony graphically describing how psychiatric survivors have been beaten, shocked, isolated, incarcerated, restricted, raped, deprived of food and bathroom privileges, and physically and psychologically abused in institutions and in their communities. The testimony pointed to the inescapable fact that psychiatric survivors are systematically and routinely deprived of their rights and are treated as less than full citizens or full human beings.

NCD has also concluded that one of the reasons public policy concerning psychiatric disability is so different from that concerning other disabilities is the systematic exclusion of people with psychiatric disabilities from policy making. They must be allowed to speak for themselves in policy-making forums.

Among other recommendations established in the report of the hearing, NCD recommends that the use of involuntary treatments, such as forced drugging and inpatient and outpatient commitment laws, should be viewed as inherently suspect and as incompatible with the

principles of self-determination. Public policy should be directed toward establishing a totally voluntary mental health system.

NCD also recommends that aversive treatments, which involve the infliction of pain or the restriction of movement for purposes of changing behavior, should be banned, since they are also incompatible with self-determination principles. Practices that often would be illegal if administered to people without disabilities are routinely used on psychiatric survivors in the name of "treatment." Such practices should shock the consciences of all Americans.

All of the recommendations in NCD's report follow the same basic principles: that people with psychiatric disabilities are, first and foremost, citizens who have the right to expect that they will be treated according to the principles of law that apply to all other citizens. All laws and policies that restrict the rights of people with psychiatric disabilities solely because of their disabilities are at odds with basic principles of law and justice, as well as with such landmark civil rights laws as the ADA.

B. White House Conference on Mental Health and Surgeon General's Report

On June 7, 1999, Tipper Gore chaired the White House Conference on Mental Health that brought together members of Congress and the Administration, people with mental disabilities and their families, mental health providers and advocates, and community, state, private sector, and foundation entities from around the country. The purpose was to announce new proposals and to expand community responses to help those with mental illnesses.

On December 13, 1999, David Satcher, M.D., Surgeon General of the United States, released a comprehensive report on mental health. The report builds on the White House Conference on Mental Health, highlighting mental illness as a public health problem that warrants national concern. The report documents sound scientific evidence for mental disorders and describes a

system plagued with treatment barriers, including stigma, discriminatory health insurance practices, and the unavailability of appropriate services. Its final chapter highlights the disparity between science and service delivery and provides the evidence base for future policy initiatives.

Unlike NCD's Report of the Albany Conference, the Surgeon General's report does not adequately address the issue of coercion. NCD shares the view of the Bazelon Center for Mental Health Law that this is especially regrettable because a climate of coercion significantly impedes the help-seeking behavior that is the Surgeon General's principal recommendation to the public.

C. EDUCATION

Efforts continued on the part of the Administration and Congress to increase opportunities for all children to learn to high standards; however, students with disabilities, parents, and advocates across the country still continue to document high levels of noncompliance with IDEA, particularly related to placement in the least restrictive environment, transition services, and the requirements for a free, appropriate, public education (FAPE).

While an amendment to the Juvenile Justice bill eroded certain due process protections under IDEA for dangerous students, another amendment nearly made it federal law that educational services may not cease for any student even if suspended or expelled. The Supreme Court decision in *Garrett F.* should increase the number of students with disabilities educated in the regular classroom. Finally, reauthorization of the Elementary and Secondary Education Act (ESEA) was not completed, leaving the review and extension of critical education provisions (e.g., school modernization, charter schools) to the second session of this Congress.

1.IDEA

A. IDEA '97 Regulations

Effective May 11, 1999, the final regulations for the IDEA amendments of 1997 appeared in the March 12, 1999, *Federal Register*. Some of the major issues addressed in the regulations are Individualized Education Programs (IEPs), assessment, discipline, and parent and regular teacher involvement. Prior to 1997, the law did not specifically address general curriculum involvement of students with disabilities. The 1997 amendments and regulations shifted the focus of IDEA to one of improving teaching and learning, with a specific focus on the IEP as the primary tool for enhancing the child's involvement and progress in the general curriculum. *NCD strongly encourages local jurisdictions to use the federal regulation as a model in developing their own guidelines for implementing IDEA and incorporating best practices drawing on their local successes.*

Also, the final regulations address the IDEA '97 provisions that incorporated prior court decisions and DOED policy that (1) allow schools to remove a child for up to 10 school days at a time for any violation of school rules as long as there is not a pattern; (2) provide that a child with disabilities cannot be long-term suspended or expelled from school for behavior that is a manifestation of his or her disability; and (3) specify that services must continue for children with disabilities who are suspended or expelled from school. *Federal policy must support solutions aimed at directing resources toward creating safe and inclusive educational environments; thorough, yet manageable, information management systems; and collaboration between parents and state and local school personnel in meeting the educational needs of all students.*

B. NCD Town Meeting on the Monitoring and Enforcement of IDEA

On September 22, 1999, NCD conducted a town meeting in Arlington, Virginia, on the enforcement and implementation of IDEA. More than 100 disability advocates, parents, and children from across the country participated in the meeting intended to highlight the release of the monitoring and enforcement report. *NCD recommends that DOED and DOJ recognize and correct the inadequacy of current federal compliance monitoring activity. School systems that*

fail to provide services required under IDEA are compromising the futures of children with disabilities. Federal authorities must develop more effective monitoring mechanisms to identify and challenge failures to comply. School systems found not in compliance must be held accountable for correcting deficiencies within specified time frames or face sanctions. Where the will to fully implement IDEA is lacking, sanctions must be applied in combination with positive incentives to change resistance to definitive action.

C. Garrett F. Supreme Court Decision

The Court held that schools are required by IDEA to provide students with nursing and/or other health-related services during the school day. (See Civil Rights.)

D. Charter Schools

A letter of informal guidance was issued in fall 1998 by the U.S. DOE D concerning the responsibility of charter schools to provide a FAPE to children with disabilities in accordance with IDEA and Section 504 of the Rehabilitation Act of 1973, as amended. It clarified that charter school programs are considered public school programs with the obligation to provide FAPE and that DOE D has broad discretion as to which enforcement options they may use to ensure full compliance. *NCD is concerned that public charter schools are being created in some jurisdictions without actually ensuring that the teachers and administrators are prepared to comply with IDEA, ADA, and section 504 of the Rehabilitation Act when children with disabilities seek to enroll. NCD encourages Congress to fund a study determining the level of compliance of charter schools with IDEA and Title II of ADA. DOED should use the full force of its enforcement powers to provide technical assistance, oversight, and monitoring to the growing number of charter schools to ensure compliance and best practices for educating students with disabilities.*

E. IDEA Amendments

Ed-Flex and two bills amending IDEA, H.R. 636 and H.R. 697, were the first of several bills introduced this year that could adversely impact children with disabilities. H.R. 636 would amend IDEA to give schools flexibility in changing the educational placement of children with disabilities by removing the 45-day maximum that a child with a disability can remain in an alternative placement. H.R. 697 would amend IDEA to allow state and local schools to establish discipline policies.

F. Juvenile Justice Bill Amendments to IDEA

IDEA suffered a devastating blow in May 1999, when the Senate voted 74–25 to amend IDEA. The amendment allows the cessation of educational services to students with disabilities who are suspended or expelled from schools for gun and/or firearms offenses.

The IDEA amendment was introduced as part of the Juvenile Justice bill, the Violent and Repeat Juvenile Offender Accountability and Rehabilitation Act. The amendment states that school personnel may expel or suspend a child with a disability for an unlimited amount of time as it would any other child, if that child carries or possesses a gun or firearm to school or to a school function. Further, the school would not be responsible for providing a free and appropriate public education during the period of expulsion.

An amendment was introduced to the Juvenile Justice bill, not IDEA, which would apply to all children and would achieve the intended objective of making schools safer. The amendment passed by voice vote. The amendment would require schools to provide appropriate interventions and services, including mental health services, to all children including children with and without disabilities removed from school for acts of violence.

2. Elementary and Secondary Education Act

ESEA was up for reauthorization this year but the committees did not complete the review and extension in time so it will be taken up in the second session of the 106th Congress. According to DOED, there are eight major themes to the Administration's proposal:

- Academic excellence in high-poverty schools
- High standards in the classroom
- Using educational technology to improve teaching and learning
- Strengthening safe and drug-free schools
- Equity, excellence, and public school choice
- Class-size reduction
- Helping limited English proficient students learn English and reach high standards
- After school programs.

All of these areas are critically important to students with disabilities and their families. *NCD encourages the President and Congress to take advantage of the opportunity provided by the ESEA reauthorization to address the need for mainstream education policy to integrate the needs of students with disabilities and students from low-income families so that the educational outcomes of all students may be improved. NCD encourages the President and Congress to use the reauthorization to*

- *ensure that students with disabilities are meaningfully included in standards-based reform and accountability systems and are expected to meet high standards, with appropriate accommodations;*
- *expand parent training and information efforts by building upon and promoting linkages with community-based parent training and information centers funded under IDEA, so that all parents can work together to promote high-quality programming that meets the individual needs of all students; and*
- *improve teacher training and professional development to better meet the diverse needs of students in mainstream settings.*

NCD strongly encourages Congress to use this legislative opportunity to amend IDEA to create a complaint-handling process at the federal level to address systemic IDEA violations occurring in a state education agency or local education agency and to provide DOJ with independent authority to investigate and litigate cases brought under IDEA.

School Modernization

Communities across the country are struggling to address critical needs to build new schools and renovate existing ones to make up for years of deferred maintenance, to accommodate rising student enrollments, to help reduce class sizes, and to make sure schools are accessible to all students and well-equipped for the 21st century.

According to a Government and Accounting Office report, one-third of all schools—about schools—need extensive repairs. The average public school in America is 42 years old, and school buildings begin rapid deterioration after 40 years. A growing body of research has linked student achievement and behavior to the physical building conditions, and conditions such as overcrowding have negative impact on the achievement of students. *NCD urges the President and Congress to pass legislation designed to provide states and localities the incentives necessary (e.g., School Modernization Tax Credit Bond, the School Renovation Loan and Grant Program) to renovate schools. NCD strongly supports the President's initiative to modernize our schools. NCD recommends that funding to support school modernization must require compliance with Title II of ADA, or a plan to achieve such compliance, thus making the new and renovated schools models of universal design. Thus, all students, teachers, and parents will be able to participate fully in all aspects of the schools of the future.*

3. Ed-Flex

The Education Flexibility Partnership Act of 1999 (Ed-Flex) gives states greater latitude in spending federal school aid. The bill makes all 50 states eligible to waive many provisions of

ESEA and the Carl D. Perkins Vocational Education Act (Perkins). Ed-Flex passed in the House (330-90) and Senate (98-1) on March 11. An IDEA discipline amendment was attached to the Senate version of the Ed-Flex bill that adds language regarding weapons possession "at school," "on school premises," and "at a school function" to Section 615(k) of IDEA 1997.

The manner in which this provision was added, that is, at the last minute with no debate, was very disturbing to disability advocates and underscores the need for ongoing vigilance to ensure that the civil rights of students with disabilities are not dismantled. Without hearings or a written report, the Senate Committee on Health, Education, Labor and Pensions reported out the Ed-Flex bill. Efforts to recommit the bill for hearings, however, were unsuccessful. Another amendment, dropped later during conference, would allow funding for hiring new teachers included in last year's omnibus spending package to be used on programs in IDEA. A third amendment authorized an additional $500 million for special education.

4. Postsecondary Education Initiatives for Students with Disabilities

Because of significant changes in education laws for persons with disabilities, the proportion of first- time, full-time freshmen with disabilities attending college increased more than threefold between 1978 and 1994, from 2.6 percent to 9.2 percent. The *Chronicle of Higher Education* reports that 17 percent of students attending higher education programs in this country have a disability. Yet research indicates that students with disabilities are less likely to enroll in postsecondary education than their nondisabled peers. Moreover, when students with disabilities attend postsecondary programs, they are more likely to attend two-year or vocational programs rather than four-year, degree-granting institutions and when they do attend, they are less likely than their nondisabled peers to persist in these programs and graduate.

The U.S. DOED's Office of Postsecondary Education has initiated a discretionary grant program to increase the number of students with disabilities who persist in attaining a four-year degree. Approximately 20 grants were funded in 1999 that provide technical assistance and professional

development activities for faculty and administrators in institutions of higher education, in order to provide a quality education to students with disabilities. This program is newly authorized by the Higher Education Act Amendments of 1998 and funded for the first time in FY 1999 at $5 million.

D. HEALTH CARE

1. Protections in Managed Care

In the 1997–1998 *Progress Report* to Congress, NCD recommended that the 106th Congress "forge a strong, enforceable ['patient's bill of rights'] in managed care and in "medical rehabilitation." This means that people with disabilities and their families have access to the quality health care they require, and that people with disabilities receive the appropriate level of necessary supports and services from medical rehabilitation professionals.

In the second report of the Presidential Task Force on Employment of People with Disabilities issued on November 15, 1999, titled *Re-Charting the Course: If Not Now, When?*, the task force recommends the following:

> Guaranteed access to emergency room services when and where the need arises; continuity of care protections so that patients will not have an abrupt transition in care if their providers are dropped; access to a fair, unbiased, and timely internal and independent external appeals process to address health plan grievances and to help govern decisions about medically necessary treatments; and an enforcement mechanism that ensures recourse for patients who have been harmed as a result of a health plan's actions.[2]

Seven major patient protection bills have been introduced in both houses of Congress since January 1999. The major area of conflict for this legislation continues to be the definition of

medical necessity. Another major issue for people with disabilities is which entity will decide what will be medically necessary—the physician or the managed care organization. In the 105th Congress, the major conflict was the structure of grievance and appeals.[3]

NCD recommends to the Congress the formulation of a comprehensive Patients' Bill of Rights that will cover the health care concerns of people with disabilities.

2. Medicaid Buy-In

Under Section 4733 of the Balanced Budget Act, states now have the option to allow individuals with disabilities who start or return to work the ability to purchase Medicaid coverage as their earnings increase, up to 250 percent of the poverty level. Currently, a number of states, including Oregon, South Carolina, Wisconsin, Minnesota, Alaska, and Mississippi, have been approved by the Health Care Finance Administration to amend their State Medicaid Plans to exercise the option of extending Medicaid coverage to eligible working individuals with disabilities. *NCD commends the President on his Executive Memorandum that directed the Secretary of Health and Human Services to ensure that governors, state legislators, and state Medicaid directors work with consumer organizations to increase public information about the State "Medicaid Buy-In." NCD also encourages other states to follow the example of the above-noted states to adopt this option in their Medicaid coverage.*

3. Medical Information Privacy

There is no comprehensive federal law that protects the privacy of people's health information. The 106th Congress had until June 1999 to develop a health privacy statute, a deadline Congress had imposed on itself in prior legislation. That same legislation requires the Secretary of Health and Human Services to issue regulations by February 2000. Because the regulatory authority of the President, through the Department of Health and Human Services (HHS), is limited, those

regulations are limited to privacy protections for medical information stored or transmitted electronically.

With Congress failing to act, the President and HHS Secretary Shalala proposed regulations that would apply to all health plans and many health care providers, as well as to health care clearinghouses such as billing companies. The regulations would (1) limit the nonconsensual use and release of private health information; (2) inform consumers about their right to access their records and to know who else has accessed them; (3) restrict the disclosure of protected health information to the minimum necessary; (4) establish new disclosure requirements for researchers and others seeking access to health records; and (5) establish new criminal and civil sanctions for the improper use or disclosure of such information.

The President indicated that the need for comprehensive federal privacy protections still exists. The HHS-proposed regulations, for instance, do not cover all paper records. They do not directly regulate many entities, including employers, other insurers, or public health agencies—thus allowing for unlimited reuse of information by such entities. Federal legislation is also needed to fortify the penalties and to create a private right of action so that citizens can hold health plans and providers directly accountable for inappropriate and harmful disclosure of information. *NCD calls upon the Administration and Congress to complete the job of enacting comprehensive protections of health information.*

The Consortium for Citizens with Disabilities, a coalition of approximately 100 national consumer advocacy, provider, and professional organizations that advocate on behalf of persons with disabilities, adopted the following principles:

> Federal legislation should statutorily establish an individual's right to privacy with respect to individually identifiable health information, including genetic information. It should prohibit the use or disclosure of individually identifiable health information absent an individual's informed consent. Legislation should guarantee an individual the right to

access his or her own health information and the right to amend such information. Such legislation should establish strong and effective remedies for violations of privacy protections. This legislation should provide a floor for the protection of individual privacy rights, not a ceiling. Finally, while protecting individual privacy rights, federal legislation should not impede important clinical and medical research.[4]

NCD concurs with these principles.

4. Physician-Assisted Suicide and Improving Pain Management

NCD finds that the countervailing arguments against permitting physician-assisted suicide outweigh its benefits. In making this finding, NCD notes that the benefits of physician-assisted suicide apply only to the small number of people who actually have an imminently terminal condition; are in severe, untreatable pain; wish to commit suicide; and are unable to do so without a doctor's involvement. Moreover, NCD notes the substantial dangers of permitting physician-assisted suicide. These dangers include the already prevalent pressures on people with disabilities to choose to end their lives and the insidious appropriation by others of the right to make that choice for them, compounded by the growth of managed care and "rationing" of health care services and health care financing. NCD also notes the societal devaluing of the lives of people with disabilities and the historical experience in the Netherlands of coercion and involuntary "euthanasia" for people with disabilities. NCD recognizes the difficulty of crafting adequate procedural safeguards, which inevitably would place unacceptable control in the hands of medical and legal "experts," and the many societal barriers that continue to limit life choices for people with disabilities. As NCD notes, "[S]ociety should not be ready to give up on the lives of its citizens with disabilities until it has made real and persistent efforts to give these citizens a fair and equal chance to achieve a meaningful life."

Events occurred during the reporting period that continue to stem the "assisted suicide" movement. Dr. Jack Kevorkian, who has assisted more than 130 people in committing suicide,

was found guilty of murder in the death of a person with Lou Gehrig's disease in Detroit, Michigan.

The U.S. House of Representatives passed the Pain Relief Promotion Act (H.R. 2260, H.Res. 339). The legislation states that pain management, even if the pain management increases the risk of death or speeds up the process of death, is a legitimate medical use of controlled substances. But assisted suicide is not. It also authorizes funding to educate health professionals on pain management. *NCD encourages the President to work with Congress to craft a federal law that will protect the human rights of people with disabilities and restrain the ability of physicians to prescribe lethal drugs as a method of physician-assisted suicide.*

In a similar vein, NCD, represented by Marca Bristo, the chairperson of the National Council on Disability, joined with the Princeton [University] Students Against Infanticide, Not Dead Yet, and others to protest the appointment of Peter Singer as a teacher of ethics to undergraduates at Princeton. Peter Singer, in his book *Practical Ethics,* writes that some people with disabilities have lives that are not worth living. Singer argues that disabled infants may be killed ethically because they are not sentient (conscious) beings. He bases this justification for killing on the future quality of life of the disabled person. Yet people with disabilities usually have a much higher perception of the quality of their lives than people without disabilities have for them.[5]

E. LONG-TERM SERVICES AND SUPPORTS

As we move to implement the Olmstead decision, there are three basic principles that all of us can agree on, now. We can agree that no American should have to live in a nursing home or state institution if that individual can live in a community with the right mix of affordable supports. We can agree that we all have the

right to interact with family and friends in our communities...to make a living...and to make a life. And we can agree that it will take time, effort, creativity, and commitment from all of us to make this a reality.

—Secretary of Health and Human Services Donna Shalala, from remarks to the National Conference of State Legislators, July 1999

NCD recognizes that the enduring inability of people with disabilities to secure consistent, affordable access to long-term services and supports is the number one reason why more people with disabilities do not live in their homes and communities and are not gainfully employed. Community-based, long-term services and supports—broadly referring to a range of services and supports for people who, because of chronic illness or disability, need assistance with activities of daily living—are finally being recast in the political arena as valid, preferred alternatives to institutional service provision.

Last year, a variety of legislative, regulatory, and judicial events converged to yield the most progressive federal policy activity to date on long-term services and supports for people with disabilities. For example, the U.S. Supreme Court decision in the *Olmstead v. L.C.* case, while qualified, was a win for proponents of home and community-based services and supports. Legislation to promote more consumer choice and long-term service system flexibility, the Medicaid Community Attendant Services and Supports Act (MiCASSA),was introduced on the heels of the passage of the Work Incentives Improvement Act (WIIA) of 1999. Family supports such as childcare and tax credits were also passed. *NCD applauds the 106th Congress for moving beyond rhetoric and implementing a strategy for dramatically expanding consumer*

choice in long-term care. NCD challenges Congress and the Administration to enact MiCASSA by the end of the 106th Congress.

1. MiCASSA

On November 16, 1999, MiCASSA was introduced in the Senate as bill number S. 1935. Co-sponsored by Senators Tom Harkin (D-Iowa) and Arlen Specter (R-Pennsylvania), the bill allows people with disabilities to have a real choice about where they receive certain types of Medicaid long-term services and supports. It also provides grants to the states to assist them as they redirect Medicaid resources into community-based services and supports.

While there have been various iterations of the bill—MiCASSA—this one would allow any person entitled to medical assistance in a nursing facility or an intermediate care facility to use the money for community attendant services and supports. NCD recognizes that personal assistance services and supports are the lowest-cost and most consumer-friendly services in the long-term care spectrum. Home- and community-based care is not only what people want; it can also be considerably less expensive. *NCD gives its strongest recommendation that Congress and the Administration enact MiCASSA by the end of the 106th Congress to meet the needs and desires of older Americans and citizens with disabilities to live in their own homes to the fullest extent possible*

2. *Olmstead v. L.C.*

In summer 1999, the U.S. Supreme Court handed down the landmark decision of *Olmstead v. L.C.* The Court recognized that unjustified isolation and segregation of persons with disabilities in institutional settings is a form of discrimination prohibited by ADA. The Court sent a simple yet profound message that long-term services and supports for people of all ages must be based on what is appropriate for and desired by the individual. (See fuller discussion of *Olmstead* on pages 18–19.)

3. Administration Efforts

The Clinton Administration proposed an ambitious, four-part, $6.2 billion (over five years) initiative to take important steps to address complex long-term care needs. The proposal included (1) a $1,000 tax credit for children with disabilities, seniors with disabilities, and their families; (2) a new National Family Caregivers Support Program; (3) a national campaign to educate Medicare beneficiaries about long-term care options; and (4) a proposal to have the Federal Government offer quality private long-term care insurance to federal employees. Most of these proposals were caught in the legislative bottleneck at the end of the session and were not funded. However, these proposals and others are among the top priorities for the second session of Congress in long-term services and support legislation.

Additionally, the Administration announced a proposal to promote more flexibility in the Medicaid program to choose home- and community-based care. Historically, Medicaid policy and practice have inadvertently discriminated against people with long-term care needs who want to live in their communities by allowing states to expand Medicaid eligibility only to residents in nursing homes. This new proposal would enable states to expand their programs to cover community-based care as well as nursing home residents with income up to 300 percent of the Social Security Income (SSI) limits.

Advocates are trying to learn how these proposals would interact with MiCASSA. This proposal would, like MiCASSA, offer people living in Skilled Nursing Facilities or Intermediate Care Facilities the choice of a home or community-based setting for their services and supports.

Other promising federal initiatives are under way to expand access to home and community-based services:

- On October 1, 1999, the Health Care Financing Administration (HCFA) and the assistant secretary for planning and evaluation (ASPE) launched the Resource

Network on Home- and Community-Based Services. The mission of this initiative is to support the work of states, the disability and aging communities, and other stakeholders who are committed to expanding access to high-quality, consumer-directed services in integrated settings in the most cost-effective way. The Network will conduct national and community forums as well as support a targeted technical assistance effort.

- ASPE and HCFA are also developing a primer to explain in clear language all that is allowable under the Medicaid long-term care program.
- Last year the two federal agencies awarded small grants to Colorado, Michigan, Rhode Island, and Texas to develop affordable ways to help nursing home residents move back into the community if they are able and willing to do so.
- HCFA recently awarded another $2 million to support similar demonstration projects in Vermont, New Hampshire, Wisconsin, and New Jersey. The grants are meant to provide states with the administrative and/or service funds necessary to remove the remaining obstacles to returning to the community.
- In partnership with the Robert Wood Johnson Foundation, ASPE and HCFA have designed and sponsored a controlled experimental test of a consumer direction model, the Cash and Counseling Demonstration. Findings from this study are expected to help identify practices that enhance consumer choice as well as practices that hamper consumer choice.

4. Child Care

Increasingly, child care is becoming a family support issue. Long-term services and support naturally include some type of quality childcare options. To receive funding under the Child Care Development and Block Grant (CCDBG), states must address in their child care plans the activities they will undertake to improve quality in child care. In order to promote the inclusion of children with disabilities in child care, the Child Care Task Force of the CCDBG recommends

that several critical activities must take place at the state level related to quality, payment rate to childcare providers, the definition of children with special needs, and collaboration.

Quality activities may include comprehensive consumer education that includes training for childcare providers, state accreditation agencies, licensing agencies, and parents on how providers can meet their responsibilities to children with disabilities in accordance with ADA.

Payment rates to childcare providers must be sufficient to enable eligible children to access high-quality childcare programs, and a separate payment rate for children with disabilities must be substantially higher than the rate charged for children without disabilities. Further, the state will need to find incentives for providers to enroll children with disabilities.

CCDBG grants each state the authority to establish a definition of children with special needs, which should be expansive enough to include the age-appropriate definitions for children ages birth through 5 found in IDEA. Head Start has adopted these definitions for its programs. The definition should also include children at risk of developmental delay, and states should report the numbers of children with special needs who are served each year by the CCDBG. Collaborative efforts should include the state lead agencies for IDEA, Grants for Infants and Families Program, and the special education preschool program. *NCD commends the President and Congress for making available funds to improve childcare options for children with disabilities and their families. NCD encourages HHS and DOED to work with the states and local governments to ensure that children with disabilities are integrated into the childcare and after-school care networks developed with the new funding. Also, in light of the fact that many states currently have waiting lists for children to get into quality childcare programs, NCD encourages the President and the 106th Congress to continue to expand the federal commitment to ensure that all children have access to quality, affordable, accessible child care.*

5. Children's Health Insurance Program

Despite the fact that the number of children enrolled in the Children's Health Insurance Program (CHIP) has grown by more than 1 million and is expected to more than double over the next year, more than 10 million children are still uninsured. On October 12, at a meeting of the American Academy of Pediatrics, President Clinton unveiled a series of steps to help enroll the millions of uninsured children who are eligible for Medicaid and CHIP. The steps include

- the first annual Interagency Report on Children's Health Insurance Outreach, which details hundreds of outreach activities by 11 federal departments and agencies;
- directing Cabinet secretaries to develop strategies to promote effective partnerships to integrate children's health insurance outreach into schools;
- new administrative guidance to state health and education officials on school-based outreach; and
- new public-private partnership between HHS and The David and Lucille Packard Foundation that will fund over $9 million to identify effective children's health insurance strategies.

More than 1,500 schools in 49 states have joined the "Insure Kids Now! Through Schools" campaign to conduct outreach for and enrollment in Medicaid and CHIP through regular school activities, including parents' nights, registration, and school physicals, and in letters sent to parents about immunization. *NCD recommends that aggressive steps be taken to increase the enrollment of uninsured children, many of whom are children with disabilities.*

F. YOUTH

An increasing number of youth with disabilities apply for SSI or SSDI each year, despite significant investments in special education. According to the Social Security Administration (SSA), approximately 60,000 youth between 18 and 24 years of age come on the rolls for SSI and SSDI annually. Among SSDI recipients, fewer than 1 percent ever leave the program.

1. Youth Task Force

In its second annual report, the Presidential Task Force on Employment of Adults with Disabilities (PTFEAD), of which NCD is a mandated member, called for a presidential directive for a cross-agency Youth-to-Work Initiative. The agencies cooperating in the Initiative would be the Departments of Labor, Education, and Health and Human Services, the Social Security Administration, the Office of Personnel Management, and other federal agencies, under the leadership of PTFEAD.

The PTFEAD report also recommended a presidential directive instructing HHS to develop a proposal allowing the Maternal and Child Health Programs for Children with Special Needs to provide Healthy and Ready to Work services to youth with disabilities who are under the age of 16.

NCD is a member of the Expanding Employment Opportunities for Young People with Disabilities Subcommittee of the PTFEAD. Specific goals and steps of the subcommittee regarding youth include

- Develop internship opportunities in the Federal Government and the private sector for young people with disabilities.

- Increase the number of young people with disabilities who pursue postsecondary education.

- Increase leadership development activities for young people with disabilities.

- Increase participation of youth with disabilities in Federal agency programs that generically target youth.

NCD strongly recommends that the focus of transition for youth with disabilities from school to work or higher education must be a broader policy perspective than the traditional IDEA and Rehabilitation Act authorities. While the linkages and practices of these two funding and program authorities clearly need independent evaluation and improvement, other program roles must be included. Within the broader workforce development systems, programs like Job Corps and apprenticeship training programs must begin to broadly include youth with disabilities. Title V Maternal and Child Health Program for Child with Special Needs must begin Health and Ready to Work Services prior to the age in which many youth with disabilities begin to drop out of school. Access to General Equivalency Degree programs must greatly expand the number of youth with disabilities taking advantage of this second opportunity at credentials necessary for access to productive, higher paying work. SSA eligibility rules must once again encourage, not discourage, higher education. NCD firmly believes the proposed presidential directive for a cross-agency Youth-to-Work Initiative must undertake its mission as an emergency priority to prevent another generation of qualified youth with disabilities from missing the only true way to economic self-sufficiency through work.

2. The 1999 National Leadership Conference for Youth with Disabilities

The June 1999 National Leadership Conference for Youth with Disabilities was coordinated by NCD and sponsored by SSA, the U.S. Departments of Education and Health and Human Services, PTFEAD, and the President's Committee on Employment of People with Disabilities. The Mitsubishi Electric America Foundation was the primary private sponsor. Over 125 youth participated in the program.

Three main purposes were established for the conference:

- First, as a forum for youth to learn from national disability leaders about national disability policy, civil rights, the public policy process and leadership, employment opportunities, and related programs available to them.
- Second, for young people to identify barriers to their economic independence, provide input to the public policy process, and identify future programs to support economic independence and leadership among all youth with disabilities
- Third, to create solidarity and community among the participants, building confidence and resolve to take action.

NCD will continue to support the National Leadership Conference for Youth with Disabilities to ensure that new generations of leaders for the disability rights movement are supported. NCD will encourage states and other entities to emulate the success of the Leadership Conference among youth with disabilities within their geographic areas.

G. IMMIGRANTS AND RACIAL AND ETHNIC MINORITIES WITH DISABILITIES

1. White House Forum on Disability and Cultural Diversity

On July 26, NCD released the executive summary from its report, *Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation*, at a White House forum on disability and cultural diversity that also celebrated the ninth anniversary of the passage of ADA. The forum, convened by the White House and NCD with support from the Leadership Conference on Civil Rights, focused on how to improve outcomes in education, employment, and civil rights enforcement for people with disabilities from diverse cultural backgrounds.[6]

NCD commends both the White House and Congress in recognizing the importance of addressing the ongoing barriers faced by people with disabilities from diverse cultural

backgrounds. At the same time, NCD proposes a multi-agency initiative to provide ongoing, intensive "know your rights" seminars in diverse communities throughout the country that would cover a range of disability civil rights laws and disability assistance programs.

NCD urges federal civil rights enforcement agencies to work together to develop culturally competent models for outreach and training on federal civil rights laws and procedures in minority racial and ethnic communities.

NCD commends the President and Congress for recognizing the need to pay particular attention to disability issues in minority communities. As the President and Congress continue to build on these first steps, NCD encourages them to address the dramatic disparities in labor force participation, health care, housing, and other areas between the general population and minorities with disabilities.

2. The President's Initiative on Race

In January 1999, the President's Initiative on Race released its final report on the Administration's effort to catalyze meaningful conversations and action on race relations in America. Along with dramatic statistics and thoughtful commentary, it included volumes of promising practices in which any citizen may engage to bring together diverse people in mutual respect and common enterprise. *NCD commends the President for launching this Initiative to help all Americans recognize our common interests and to bridge the opportunity gaps that are keeping us from becoming an America for all.*

3. Restoration of Legal Aliens' Eligibility for Disability and Health Benefits

Upon signing the 1996 welfare reform law, President Clinton made a commitment to reversing unnecessary cuts in benefits to legal immigrants that had nothing to do with the law's goal of moving people from welfare to work. Though the Balanced Budget Act protects the most

vulnerable, restoration of important disability and health benefits to additional categories of legal immigrants still remains to be completed.

The Balanced Budget Act of 1997 and the Noncitizen Benefit Clarification and Other Technical Amendments Act of 1998 invested $11.5 billion to restore disability and health benefits to 380,000 legal immigrants who were in this country before welfare reform became law (August 22, 1996). Restoration of eligibility for SSI and Medicaid to legal immigrants who enter the country after that date, if they have been in the United States for five years and become disabled after entering the United States, should be the next step in policy. *NCD calls upon the Administration and Congress to restore this program eligibility and the funds to support it.*

H. SOCIAL SECURITY WORK INCENTIVES AND SSA AND MEDICARE SOLVENCY

1. Work Incentives Improvement Act

On December 17, 1999, President Clinton signed WIIA, the last Act to become law in the millennium. This landmark legislation gives people with disabilities the opportunity to move into employment and reduce their dependence on benefits and other assistance. It does not address all issues, but it does bring positive change, while balancing the concerns of key stakeholders.

WIIA improves access to health care by (1) expanding states' ability to provide a Medicaid buy-in to people with disabilities who return to work; and (2) extending Medicare coverage for people with disabilities who return to work WIIA also improves access to health care by creating a new Medicaid buy-in demonstration to help people with a specific physical or mental impairment that is not severe enough to qualify for health assistance, but is likely to lead to a severe disability in the absence of medical treatment.

In addition, WIIA will modernize the employment services system by creating a "ticket to work and self sufficiency" that will enable SSI or SSDI beneficiaries to go to any public or private provider for vocational rehabilitation. It provides beneficiaries with disabilities both choice and expanded options in pursuing employment and employment supports.[7]

Like President Clinton, NCD challenges the states to take advantage of the new $250 million demonstration program that tests whether early medical intervention, made accessible by Medicaid coverage, will enable people with such disabilities as muscular dystrophy, Parkinson's Disease, or diabetes to stay healthier and keep working.

NCD notes that there are no incentives in WIIA for ongoing supports and services, particularly that segment of the disabled population who experience mental retardation, developmental disabilities, or other significant disabilities. The concern is that the ticket will result in "creaming" of those individuals who are less costly to serve and easier to place in jobs, leaving those with more significant disabilities described above with little hope of assistance.

As regards providers of services, the individual with a disability may not change networks during the five years of ticket payment without showing "good cause." The choice of providers should have fewer constraints, not more.

NCD recognizes that WIIA *is not as enforceable as ADA. The realization of economic advancement is not automatic, let alone guaranteed. Individual states need to be persuaded that WIIA is good government, and good for every citizen.*

NCD encourages the Secretary of Labor to develop step-by-step technical assistance programs to demonstrate how WIIA can be integrated into the 1998 Workforce Investment Act (WIA) implementation activities.

2. Social Security Solvency

SSA flatly states that Social Security benefits will be there for current beneficiaries and future generations. Forty-four million people receive retirement, survivors, and disability benefits from the program. More than six million workers and family members receive disability benefits.

NCD notes that the White House Conference on Social Security Solvency included a significant number of disability advocates and persons with disabilities. NCD commends the White House on the inclusion of advocates and persons with disabilities in that conference.

NCD encourages the Secretary of Labor to develop step-by step technical assistance programs to demonstrate how WIIA can be integrated into the 1998 WIA implementation activities.

NCD continues to encourage the President and Congress to ensure the meaningful inclusion of people with disabilities and their families in discussions about the projected shortfall of the Trust Fund; preserve the guarantees inherent in the disability insurance program and the protections for survivors and dependents in the Old Age, Survivors, and Disability Insurance programs of Title II of the Social Security Act; protect the integrity of the benefits provided so that they are at a reasonable level for support; protect the value of the benefits so that the buying power of the benefits does not diminish with inflation; and, finally, to take into account any potential effect on the SSI program when assessing the impact of any reform proposal.

Finally, NCD encourages the White House and the 2nd Sessions of the 106th Congress to work together in forging these long-term reforms.

3. Medicare Reform

In previous actions, NCD recommended to the Bipartisan Commission on the Future of Medicare that working-age Medicare enrollees with disabilities be consulted and have input on how Medicare could better meet their needs. NCD also asked the President and Congress to make the

scope of coverage under Medicare provide the kinds of services and supports that working-age people with disabilities require.

NCD recommends a comprehensive, bipartisan plan to strengthen and modernize Medicare. Such a proposal must make the program more efficient and competitive and increase access to preventive care critical to individuals with disabilities to prevent the development of secondary conditions. The proposal must dedicate a portion of the existing budget surplus to keep Medicare solvent past 2025 and help to pay for a long overdue voluntary prescription drug program.

I. EMPLOYMENT

> *We need to do more to expand employment opportunities; expand educational opportunities; invest in new technologies to make our society more accessible; and enforce our civil rights laws—so discrimination on the basis of disability becomes an ugly relic of the past.*
>
> —Vice President Albert Gore

1. The Workforce Investment Act of 1998

The WIA of 1998 included the Rehabilitation Act Amendments of 1998. NCD encouraged the Rehabilitation Services Administration (RSA) to work closely with PTFEAD to develop multi-agency demonstration and research initiatives. These initiatives should increase dramatically the rate of employment of people with disabilities and should provide policy options for RSA that addresses the range of disincentives that prevent people with disabilities seeking employment from succeeding. *To that end, NCD commends the report of the Presidential Task Force that notes the efforts of DOED's RSA, the Department of Labor's Employment and Training*

Administration, and SSA to address the issues of physical and program access in the implementation phase of WIA. This joint effort includes technical assistance on assistive technologies, compliance issues, customer service, and participation of people with disabilities in the One-Stop Career Center systems.

Still, NCD recognizes that this multi-agency approach to delivery of services for the employment of people with disabilities in order to increase the employment rate for this population needs to be improved. The era of isolated, specialized services for people with disabilities is over. Federal agencies cannot work in isolation.

In addition, mainstream employment and training networks should implement a comprehensive training module so that line staff are well informed about resources available for people with disabilities seeking employment and are well equipped to meet the needs of clients with a wide range of disabilities.

2. Job Training and Vocational Rehabilitation

The Department of Labor (DOL) issued an Interim Final Rule implementing Section 188 of the WIA. Essentially, this section contains the statute's equal opportunity and nondiscrimination provisions. The WIA supersedes the former job training programs as DOL's primary mechanism for providing financial assistance for a comprehensive system of job training and placement services for adults and eligible youth. DOL's Interim Final Rule became effective on November 12, 1999. The Civil Rights Center of DOL is the agency responsible for administering the nondiscrimination and equal opportunity provisions of WIA.

RSA issued an Information Memorandum titled *A Guide for Developing Memoranda of Understanding with Local Workforce Investment Boards as Required by the Workforce Investment Act*. This Guide is designed as a framework for negotiations in the development of the memorandum of understanding (MOU). Components are drawn from the WIA requirements

for a memorandum and from questions submitted by individuals with disabilities, community rehabilitation programs, and state vocational rehabilitation programs.

NCD recognizes the release of the Information Memorandum as a significant step, but encourages RSA to expedite its technical assistance and policy guidance moving vocational rehabilitation programs into a meaningful partnership with WIA in the multi-agency One Stop workforce development system.

Through their respective discretionary programs and joint funding, DOL's Employment and Training Administration (ETA), SSA, and RSA have funded state and/or local projects to encourage the development of interagency coordination best practices. Coordination of evaluation strategies on the progress of these five-year projects is also being planned.

NCD commends ETA, SSA, and RSA on this interagency cooperation that may be a model for interjecting coordination practices into the requirements of all discretionary grants supporting the employment of individuals with disabilities. In addition, they may well provide the best practices of the future for state-level coordination in workforce and health care programs that serve people with disabilities.

3. Substantial Gainful Activity Rule Revised

SSA revised the rules for determining when earnings demonstrate the ability to engage in "substantial gainful activity" (SGA). The rule became effective on July 1, 1999. SSA raised the average monthly earnings guideline from $500 to $700 to determine whether work done by persons with impairments (other than blindness) is SGA. The purpose is to encourage individuals with disabilities to attempt to work, and to provide an updated indicator of when earnings demonstrate the individual's ability to engage in SGA. SSA believes that this is a significant improvement to work incentives.

NCD commends Social Security for making this rule change from $500 to $700. Three thousand comments were received from individual stakeholders (e.g., advocates, state and local government entities, attorneys, SSA field office staff, a member of Congress, and private citizens). Practically all of the respondents were in favor of the increase. Many of the respondents recommended that SSA should make further changes and NCD concurs in this opinion.

4. Social Security Administration Next Steps

- Establishment of SSA Office of Employment Support Programs. In August of 1999, SSA established the new executive Office of Employment Support Programs to improve quality of service to people with disabilities who want to work.

- Small Business Administration (SBA) and SSA MOU to help improve employment and entrepreneurial opportunities for people with disabilities. The two agencies signed a partnership agreement on October 20, 1999, to coordinate the efforts of SBA's Welfare-to-Work Initiative and the SSA's Disability Insurance and SSI programs to help adults with disabilities find gainful employment or become entrepreneurs. One purpose is to link small businesses seeking workers with Americans with disabilities. Each agency will encourage its field offices to cooperate at the local level, share information about business and nonprofit organizations that train beneficiaries with disabilities, and work together on job fairs and other community outreach activities.

NCD commends both SSA and SBA on signing this MOU to help in developing small business and entrepreneurial activities to increase the employment rates of adults with disabilities to be as close as possible to that of the general adult population.

5. Tax Credit

On January 13, 1999, the President announced a new proposal that will allow workers with significant disabilities to receive an annual $1,000 tax credit to help cover the formal and informal costs associated with employment, such as special transportation and technology. Like the Jeffords-Kennedy-Roth-Moynihan Work Incentives Improvement Act, this tax credit, which will assist 200,000 to 300,000 Americans, will help ensure that people with disabilities have the tools they need to return to work. Congress did approve the President's proposal. In addition, the Work Opportunity Tax Credit (WOTC) was extended to December 31, 2001, and made effective retroactively back to June 30, 1999, when it expired. WOTC provides a tax credit to employers who hire individuals, such as individuals with disabilities, in vocational rehabilitation programs.

6. Presidential Task Force on the Employment of Adults with Disabilities

President Clinton signed Executive Order 13078 on March 13, 1998, to establish PTFEAD. The Task Force mandate is to examine the programs and policies related to the employment of adults with disabilities to *"determine what changes, modifications, and innovations may be necessary to remove barriers to work faced by adults with disabilities"* and to recommend options for such changes. *"The ultimate mission of the Task Force is to create a coordinated and aggressive national policy to bring adults with disabilities into gainful employment at a rate that is as close as possible to that of the general adult population."*

NCD and PTFEAD recommend to the President the following:

To direct the Department of Labor to develop a proposal, for consideration in the 2001 budget process, for the establishment of an Office of Disability Policy, Evaluation, and Technical Assistance (ODPET) to be headed by an Assistant Secretary of Labor. ODPET would ensure ongoing efforts to integrate people with disabilities into DOL's mainstream employment and training programs; establish the National Disability Business Development Board to serve as an advisory body to ODPET; maintain the principal functions of the President's Committee on Employment of People with Disabilities; and, finally, assist PTFEAD in implementing a coordinated and aggressive national employment strategy for people with disabilities.

7. Federal Government's Commitment to Hire People with Disabilities

The President directed the Office of Personnel Management (OPM) to explore ways to eliminate the stricter standards applied to Federal job applicants who have psychiatric disabilities. On June 4, 1999, President Clinton signed Executive Order 13214 amending the civil service rules relating to federal employees with psychiatric disabilities. The same rule that allows people to convert after two years from noncompetitive status to competitive status without an examination (for people with severe physical disabilities and mental retardation) applies now to employees with psychiatric disabilities.

Vice President Gore directed OPM to develop a model plan to increase the representation of adult employees with disabilities through federal employment. The President directed federal agencies to implement the comprehensive plan immediately.

An interagency task force, the Federal Government as a Model Employer Committee was established through PTFEAD and focuses on the Federal Government's commitment to hire persons with disabilities.

NCD commends the Administration on the Executive Order in the hiring of people with psychiatric and other disabilities. At the same time, the existing laws(e.g., ADA and Sections

503 and 504 of the Rehabilitation Act) must be leveraged for creating change in both the public and private sectors. For example, Federal contractors employ approximately 26 million people, or nearly 22 percent of the total civilian workforce. This is a critical area for influencing the employment of people with disabilities. Federal contractors need more information on Section 503 compliance and best practices in their hiring strategies.

On October 16, 1999, the President released a plan titled *Accessing Opportunity: The Plan for Employment of People with Disabilities in the Federal Government* along with an employment guide prepared by OPM.

NCD commends the President for giving federal agencies detailed and practical information on ways to recruit people with disabilities for positions at all levels of government; to provide opportunities for students with disabilities; to ensure career opportunities for people with disabilities; to collect and maintain data to monitor their success; and to provide reasonable accommodations for applicants and employees with disabilities.

J. WELFARE-TO-WORK

1. Federal/State Efforts

The goal of the 1997 Welfare-to-Work Initiative was to move the hardest-to-serve welfare recipients into unsubsidized jobs and economic self-sufficiency by funding grants to states and local communities for job creation, job placement, and retention efforts (e.g., wage subsidies). Even though welfare caseloads are at their lowest level in 30 years, the individuals remaining on the rolls tend to be recipients with the greatest challenges to employment: long-term recipients with poor work histories, low basic skills, or substance abuse problems. The program also serves noncustodial parents with barriers to employment whose children are long-term welfare recipients.

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A Department of Labor Welfare to Work research report, prepared by the Brookings Institute, indicates that the few research studies available have begun documenting the widespread occurrence of disabilities—particularly learning disabilities—among welfare recipients and the high correlation between disabilities and unsuccessful efforts at employment. If this population of welfare clients is to make a successful transition from welfare to work at a sustaining wage, agencies must accurately diagnose clients' needs and explore opportunities for workplace accommodations.

2. Welfare Recipients with Disabilities

The report established the following estimation of need for special services among welfare recipients with physical (unable to work) and learning disabilities:

Percentage of the Welfare Population Facing This Issue	
Work-Related (Physical) Disabilities	
National estimates:	10 to 20 percent
State/local estimates:	11 to 31 percent
Learning Disabilities	
National estimates:	25 to 40 percent
State/local estimates:	36 to 66 percent

Other findings of the report include:

Relationship to Welfare Receipt

- Female welfare recipients are more than four times as likely as nonrecipients to have very low basic skills.
- People receiving welfare five years or longer are almost twice as likely to have very low basic skills than are those receiving welfare less than two years.

- Among welfare recipients in a recent study, those with special learning needs received welfare for 79 months, compared to 61 months for those who did not have special learning needs.

Relationship to Employment Status

- People with any level of disability are much less likely to be employed than those without a disability, and they have a greatly reduced earnings capacity.
- People who report having work disabilities are more than twice as likely as other workers to be unemployed but actively seeking work—16 percent versus 7 percent.
- Welfare recipients with functional limitations are half as likely to exit welfare for work in a given four-month period than recipients without functional limitations.
- A large proportion of adults with learning disabilities are thought to drop out of job training efforts because the programs are not designed to meet their learning needs.

The report recommends the following steps that welfare agencies should take to better serve clients with disabilities:

- **Program Staff**. If program implementation is to be successful, welfare agencies must make a substantial commitment to training staff on disability issues, particularly on how to use screening and assessment tools to identify clients with disabilities.

- **Coordinated Delivery of Services.** To serve clients with disabilities successfully, welfare agencies should develop partnerships with other organizations for the provision of remediation, rehabilitation, and employment-related services.

- **Service Capacity.** To serve clients with disabilities successfully, welfare agencies must assess the extent to which current local service capacity helps to serve,

rehabilitate, and employ clients with disabilities and, where gaps exist, address the shortage.

The Welfare-to-Work Initiative has been extended, and several states, including Missouri, Wisconsin, and Nevada, have targeted all or a significant amount of their Welfare-to-Work funds to serving noncustodial parents. *NCD commends the President and Congress for recognizing the need to address housing, transportation, and other barriers to enable people on welfare to obtain and retain employment. NCD encourages another extension of the Welfare-to-Work program. NCD encourages the President and administering agencies for these new programs to recognize that a large percentage of the population remaining on Temporary Assistance for Needy Families has disabilities ranging from learning disabilities to psychiatric disabilities to substance abuse issues. Accordingly, many of these individuals must have their disability-related needs addressed in order for the goal of obtaining long-term employment to be realized. Moreover, NCD encourages the President and Congress to recognize that the current efforts to move people from welfare to work may have important lessons for the growing effort to move people from reliance on disability benefit programs to employment. Issues such as housing, transportation, and health care must be addressed for the SSI and SSDI populations as well, if the transition to work is to be successful.*

K. HOUSING

In FY 1999, policy changes in the definition of housing for individuals with disabilities, the concept of visitability, and an emphasis on TBRA and home ownership began to be a part of the practices and operations of HUD. This integration of earlier policy victories into the operations of federal housing agencies establishes the environment of statistical support and program successes necessary for further policy changes toward a true civil rights approach to meeting the housing needs of Americans with disabilities.

1. Section 8 Mainstream Housing Opportunities for Persons with Disabilities Program

Increased TBRA and Section 8 portable vouchers became a larger part of housing policy when HUD's Notice of Fund Availability allowed 50 percent of its section 811 program funds (Supportive Housing for People with Disabilities) for TBRA. On March 8, 1999, HUD allocated $88.5 million for Section 8 rent subsidies targeted to people with disabilities. Because of a significant modification in the Section 8 Mainstream Housing Opportunities for Persons with Disabilities Program, for the first time, nonprofit disability organizations are eligible to apply. Previously, only Public Housing Authorities were eligible to apply and only a woeful 10 percent were willing to do so, leaving no other way for people with disabilities to obtain these rent subsidies in their communities. Congress urged HUD to make this modification during the 1999 budget process and has made available $48.5 million in five-year rent subsidies. *NCD commends HUD for doubling the traditional 25 percent of 811 funds available for TBRA activities. Congress is commended for broadening the access of the Section 8 Mainstream funds to nonprofit organizations. NCD still recommends that 100 percent of the section 811 program funds be used for person-based, rather than project-based, housing resources. This change would be consistent with the requirements in section 504 of the Rehabilitation Act and the Fair Housing Act that housing resources be provided in the most integrated setting appropriate.*

Also critical to the wider use of TBRA is the availability of modification funds for low-income individuals with disabilities. HUD's continued notification to cities and housing authorities encouraging the use of Community Development Block Grants for home modification of rental-home-owned properties for individuals with disabilities has assisted. *NCD encourages HUD to build on these steps by creating a national home modification fund for low-income people with disabilities, both renters and owners. HUD thereby will empower more people with disabilities to become homeowners or tenants in community settings.*

2. Home Ownership

Home ownership for low-income individuals with disabilities moved forward with implementation of the Quality Housing and Work Responsibility Act of 1998, Title V of P.L. 105-276. Provisions of the Act allow for home ownership with the Section 8 TBRA funds described above.

3. Visitability

In HUD's continued HOPE (Housing Opportunities for People Everywhere) VI Notices of Funding Availability, the agency included bonus points for developers when they seek to build or rehabilitate structures with three or fewer units that include visitability by people with disabilities. This visitability concept would require all such new housing to have at least one no-step entrance and 32-inch doorways so people with disabilities could visit their friends who live there. HUD's commitment to a visitability policy was strengthened with the publication of a guide by the Office of Public and Indian Housing explaining basic access design. *NCD commends HUD for embracing visitability as a goal for HUD-financed housing and for recognizing that the move from project-based housing to town homes and other detached dwellings does not need to mean a reduction in accessibility if developers are encouraged to build in such features in the design stage.*

4. Compliance with Section 504 of the Rehabilitation Act by HUD and Its Grantees

Concerns among self-advocates with disabilities remain regarding the continued segregative housing practices and policies in Section 811 programs that place individuals with disabilities into diagnosis-specific housing and services of a residential provider. An example is the new programs announced by HUD under the McKinney Continuum of Care Homeless Assistance Programs.

In February 1999, HUD announced three programs that can provide housing for people with disabilities who meet the HUD definition of homeless, that is, people who are living on the streets, in emergency shelters, or in a transitional housing program. These programs include

- the *Supportive Housing Program* allowing the development of transitional housing or supportive services for homeless people,
- the *Shelter Plus Care Program* funding permanent housing for homeless people with disabilities with rental subsidies that are matched with an equal amount of service funding, and
- the *Section 8 Moderate Rehabilitation for Single Room Occupancy (SRO) Dwellings* providing 10-year project-based rent subsidies to rehabilitate permanent housing for homeless individuals.

HUD set aside 30 percent of the total funding made available through the McKinney Homeless Assistance Program to be used to fund permanent housing projects for homeless persons including the Supportive Housing Program—permanent housing for persons with disabilities. It is this type of housing that likely segregates this group of individuals with disabilities into a geographical area with support services linked to a single provider system. *NCD recommends that HUD reform the programs under which people with disabilities receive assistance with housing to ensure that these programs reflect the most integrated setting requirement of section 504 and independent living philosophy of the disability rights movement.*

L. TRANSPORTATION

> *The programs and policies we are announcing today affirm that transportation is about more than concrete, asphalt, and steel. It is the means by which people get to where they need to go: to jobs,*

to schools, to markets. All Americans must have access to all opportunities our great nation offers. Accessibility is a civil right.

—Secretary of Transportation Rodney E. Slater

On the ninth anniversary of ADA, Secretary of Transportation Rodney E. Slater announced a new departmental policy on accessibility as well as action items to ensure access to transportation for people with disabilities. The policy statement is to ensure access for people with disabilities to all modes of transportation, including trails and walkways, and DOT's action items include chartering a ONEDOT accessibility task force composed of representatives from all modes of transportation to develop programs and benchmarks to help ensure transportation access for all Americans.

1. NCD Air Travelers Report

On February 26, 1999, NCD submitted the first in a series of reports on enforcement of federal laws protecting the civil rights of children and adults with disabilities, titled *Enforcing the Civil Rights of Air Travelers with Disabilities: Recommendations for the Department of Transportation and Congress*. The ACAA enforcement study reports some of the facts explaining why, 12 years after the law was enacted, people with disabilities continue to experience so much discrimination. The causes are many and complex, but a lack of strong federal enforcement has been a big contributing factor. Some of the most serious deficiencies in enforcement include

- Severe understaffing and underfunding: DOT's budget and staff for ACAA enforcement are too small to be effective.

- Inadequate public education efforts: The majority of people with disabilities who travel by air do not know about their rights under the law. A major public education effort is needed to inform the public about the legal rights of air travelers with disabilities and

how to obtain these rights.

- Insufficient monitoring of disability complaints received directly by airlines: DOT monitors the discrimination complaints it receives against each airline and meets regularly with the airlines to discuss them. DOT does not, however, monitor the complaints received directly by airlines, which are 36 to 100 times the number received by DOT.

- Inadequate technical assistance and inconsistent monitoring of airline compliance: There is no formal technical assistance program designed to help airlines comply with regulatory requirements and solve implementation problems. When problems are found during compliance reviews, follow-up is not consistent to ensure that airlines take corrective action.

Weaknesses in the law itself undermine ACAA enforcement:

- Civil penalties are too small to be effective, where a formal complaint has resulted in a finding of discrimination. The current maximum civil penalty is $1,100 per discrimination offense.
- Plaintiffs who bring a civil lawsuit and win are not entitled to reasonable attorney's fees under law, or even compensatory damages.

- Foreign air carriers operating in the U.S. market are not subject to ACAA nondiscrimination requirements. Although prohibited from "unreasonable discrimination" under another provision of the Federal Aviation Act, the provision was not successfully applied to a disability discrimination claim against a foreign air carrier until September 1998.

2. DOT Action in Response to NCD Report

Air Carriers Access Act

During the summer of 1999, DOT formally charged Continental Airlines with violating the ACAA and offered to work with them to make corrections under the law. The action against the air carrier started with consumer complaints of inadequate employee assistance to travelers using wheelchairs and stowing wheelchairs in the storage compartment with luggage instead of in the passenger cabin as required by DOT regulations.

DOT Rulemaking on Compensation for Damages to Assistive Devices

As part of the Clinton Administration's ongoing efforts to ensure fair treatment for airline passengers with disabilities, a new rule to eliminate airline liability caps for damage to wheelchairs and other assistive devices was instituted. "Now passengers with disabilities can recover burdensome repair or replacement costs if their wheelchairs are lost or damaged in flight." The new rule makes final a proposal issued on February 19, 1999.

NCD urges DOT to seek additional resources for enforcement of ACAA and to target specific areas where it will initiate action, in concert with the disability community, the aviation industry, and other stakeholder groups, to correct persistent implementation and compliance problems. NCD encourages DOT to establish an ACAA civil rights enforcement unit that is separate from consumer affairs monitoring to investigate allegations of discrimination.

NCD also encourages Congress to increase DOT's ACAA enforcement budget and to amend ACAA, through reauthorization of the Federal Aviation Act, extending its nondiscrimination mandate to all airlines serving U.S. markets, strengthening DOT's enforcement mandate, and authorizing those whose civil rights have been violated to obtain appropriate legal remedies.

3. Over-the-Road Bus Rule

On April 1, 1999, DOT published a notice of request for comments on its final rule on accessibility of over-the-road buses that requires bus companies to document lack of service to people with disabilities. The final rule has four different record-keeping and reporting requirements. The first deals with 48-hour advance notice and compensation. The second has to do with equivalent service and compensation. The third deals with reporting information on the number of riders on accessible fixed-route buses. The fourth has to do with reporting information on the purchase and lease of accessible and inaccessible new and used buses.

The purpose of the information collection requirements is to provide data that DOT can use in its regulatory review and to assist DOT in its oversight of compliance by bus companies. In addition, DOT allocated $2 million in Federal Transit Administration Over-the-Road-Bus grants from a program created by the Transportation Equity Act for the 21st Century (TEA-21) for training and to assist in the incremental capital costs of making over-the-road buses wheelchair accessible.

4. Greyhound Settlement

The DOJ reached an out-of-court agreement with Greyhound, the nation's largest intercity bus company, after allegations of discrimination were leveled against it. Greyhound will pay damages and agreed to take steps before regulatory deadlines to phase-in lift-equipped buses. The bus company also agreed to train all of its employees in assisting riders with disabilities and to create other policies and procedures to improve transportation options.

NCD strongly encourages enforcement strategies on the over-the-road bus regulations to erase the brazen disregard for the law, demonstrated by the largest intercity bus company, since the passage of the ADA. The data collection provisions of the over-the-road regulations, coupled with the DOJ settlement, provide DOT with basic information for

altering enforcement and technical assistance activities to ensure full compliance by the date established in the regulations.

M. TECHNOLOGY AND TELECOMMUNICATIONS

Technology and telecommunications are becoming increasingly more critical factors in the education, employment, and independence of the daily lives of all Americans. Making sure individuals with disabilities have equitable access to technology and telecommunications becomes imperative for these same aspects of their lives. Recent legislation is in place to bring us closer to this goal. The Federal Government's strong enforcement of these laws, reinforcement of research in universal design in technology and telecommunications systems and products, and use of its huge purchasing power in accessible electronic and information technology becomes the focus of determining progress in disability policy in this area.

1. Section 508 of the Rehabilitation Act Amendments

The Workforce Investment Act of 1998, signed into law on August 7, 1998, contains amendments to the Rehabilitation Act of 1973. The changes to section 508 of the 1998 amendments to the Rehabilitation Act were designed to strengthen enforcement of long-standing law obligating federal departments and agencies to provide accessible technology and information to individuals with disabilities, including employees and members of the public.

The changes in the enforcement provisions of section 508 require federal agencies to conduct a self-evaluation of the accessibility of their electronic and information technology and provide the results to the Attorney General for a report to the President by February 7, 2000. Authority was given to the Access Board for issuing accessibility standards by February 7, 2000. The General Services Administration (GSA) and federal agencies are required to incorporate the standards into their acquisition regulations for purchasing electronic and information technology by August

7, 2000. Finally, individuals with disabilities employed by or receiving services from these agencies can file complaints under similar provisions established under Section 504. Progress on implementing these enforcement provisions to date is detailed below.

Attorney General

On April 2, 1999, the Attorney General issued a memorandum to all federal agencies and departments advising them of the requirements of Section 508 and providing instructions and documents for conducting self-evaluations of the extent their electronic and information technology is accessible to and useable by individuals with disabilities. A report of the self-evaluation results was due to the Attorney General by June 15, 1999. The report to the President is being prepared.

Access Board

The Access Board appointed the Electronic and Information Technology Access Advisory Committee (EITAAC) to develop recommendations for section 508 standards. EITAAC issued their final report May 12, 1999. The report provides recommended standards for federal procurement officers and commercial suppliers of electronic and information technology and services that will result in access to and use of the technology and information by individuals with disabilities, as well as recommendations addressing their implementation through the federal procurement system.

The next step for the Access Board is the issuance of a Notice of Proposed Rule Making, based upon the EITAAC recommendations, establishing the standards required by the Act. The regulatory process is time consuming and the Board will not meet the February 7, 2000, deadline.

General Services Administration

The GSA has received an appropriation of $2.5 million to enable it to procure assistive technology for the larger federal agencies and to better ensure that these agencies are able to fulfill technology access for its employees. GSA has also received $1 million to test hardware and assistive technology, and to help fully implement Section 508. Specific strategies for use of these funds are still in the development stage.

NCD recommends that the Access Board, the Office of Management and Budget, and the GSA expedite the issuance of standards and the necessary changes to federal and agencies' acquisition regulations to ensure implementation of Section 508 statutory requirements prior to the end of fiscal year 2000.

2. Federal Communications Commission

Section 255 of the Telecommunications Act

The Federal Communications Commission (FCC) released final regulations implementing section 255 of the Telecommunications Act of 1996 on September 29, 1999. The regulations implement the mandate of section 255 that telecommunications service providers and equipment manufacturers must make their services and equipment accessible to people with disabilities, to the extent that it is readily achievable to do so. Supporting the recommendations of the disability community, the commission identified authority to include e-mail, voice mail, and other common communication tools within the definition of "telecommunications." The final report also included a Notice of Inquiry proceeding to study how the development of Internet telephony will impact accessibility.

Video Description

On November 18, 1999, FCC proposed that commercial television broadcasters in the top 25 television markets, and the largest national video programming distributors, introduce video description in a portion of their transmissions to allow individuals with visual disabilities to better follow the visual action in television programs.

FCC Reorganization

FCC created two new bureaus, the Enforcement Bureau and the Consumer Information Bureau, effective November 8, 1999. The organizational change strengthens FCC's ability to serve the public by improving the effectiveness of the agency's enforcement program in a competitive marketplace. It also improves the ability of consumers to obtain quick, clear, and consistent information about their rights under communications laws. A Disability Rights Office is also established within the Consumer Information Bureau to provide guidance to the commission on disability accessibility policy and to ensure that individuals with disabilities benefit from the progress of telecommunications.

E-Rates

The 'e-rate,' part of the Telecommunications Act of 1996, is providing $2.25 billion in 20 to 90 percent discounts to connect schools and libraries to the Internet, with the deepest discounts going to the poorest schools that need it most. The e-rate alone has provided Internet access for children in more than a million classrooms.

NCD commends FCC and Chairman Kennard for pressing accessibility issues within the Telecommunications Act and continuing the cause for an accessible communications and technology environment with its efforts in Internet telephony and voice description. NCD challenges the Disability Rights Office to work with the disability community to push the commission further in this cause.

3. Research and International Developments

A $23 million request by the Administration for technology initiatives for the National Institute on Disability and Rehabilitation Research—$8 million for initiatives in information technology and telecommunications, and $15 million for grants to states for alternative loan financing programs—was reduced by Congress to $5 million and $4 million respectively. *NCD commends the Administration for recognizing the need for increased funding in technology research and making technology affordable to all individuals with disabilities, and encourages Congress to meet the President's recommended funding levels.*

Progress in international technology access policy included the Irish and Portuguese governments issuing requirements that all government websites must be accessible to persons with disabilities. The World Economic Development Congress publication "World Markets in 2000" selected the web accessibility article "The Growing Digital Divide in Access for People with Disabilities: Overcoming Barriers to Participation" for distribution at their World Bank International Monetary Fund (IMF) Summit and to government cabinets around the world. The article was developed for the first U.S. conference on the impact of the digital economy, convened by President Clinton.

N. INTERNATIONAL ISSUES

The year 1999 witnessed several important successes for people with disabilities around the world. On March 1, the International Treaty to Ban Landmines became international law, having been ratified by 40 countries in just eight months. The treaty is a critical step in eliminating landmines; landmines continue to create physical impairments among people worldwide. In July, the Organization of American States ratified the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities. The U.S. Agency for International Development (USAID) issued its first year self-assessment of its policy to

integrate disability concerns into all development activities of the agency. The World Bank extended its look at economic development and the need to incorporate strategies to serve populations with disabilities. However, a 1991 General Accounting Office report entitled "Assistance to Disabled Persons in Developing Countries" characterizes U.S. assistance as "sporadic." As of 1999, this assessment remains accurate.

1. World Bank

In a recent review of poverty and disability commissioned by the World Bank, the author concludes: "Disabled people have lower education and income levels than the rest of the population. They are more likely to have incomes below poverty level than the nondisabled population, and they are less likely to have savings and other assets... The links between poverty in disability go two ways—not only does disability add to the risk of poverty, but conditions of poverty add to the risk of disability." The impact of this relationship is apparent in every development sector.

The Bank is developing and extending its products and services to help its clients meet this development challenge. There is a growing portfolio of Bank projects that include persons with disabilities. Increasing the *quality* of such projects is a high priority and will be accomplished through the collection of information on good practice in development assistance for disabled persons and distribution of this information in supports for project design. The Bank will continue to strengthen its efforts in partnership with clients and other organizations to build and disseminate good practices in order to help countries achieve the goals of access, inclusion, and poverty reduction of persons with disabilities.

NCD encourages the World Bank to ensure that all assistance is developed and delivered in a manner that ensures full participation and accessibility by all people with disabilities in the geographic region served by the aid or assistance.

2 U.S. Department of State

Last year, NCD encouraged the Department of State to take steps to ensure that all aspects of U.S. foreign policy and assistance recognize the human rights and civil rights of all people with disabilities, by ensuring compliance with the Architectural Barriers Act, Section 504 of the Rehabilitation Act, and ADA in U.S. embassies, consular offices, missions, and other U.S.-owned or -leased property abroad. Progress in this area includes the completion of the survey of U.S. embassies and residences and the establishment of accessibility to these facilities as among the five priorities for renovation and new construction. Affirmative action in hiring practices by the Department of State has seen increases in the placement of individuals with disabilities in positions from internships up to Foreign Service Officers. Much more remains in the completion of self-evaluations in all U.S. government agencies active abroad, as mandated by Section 504 of the Rehabilitation Act.

Also last year, NCD encouraged the Department of State and USAID to ensure that all foreign aid and assistance is developed and delivered in a manner that ensures full participation and accessibility by all people with disabilities and their families in the geographic region served by the aid or assistance. The State Department has yet to issue a policy statement to that effect, though negotiations continue.

3. U.S. Agency for International Development

In its 1996 reports *Foreign Policy and Disability* and *Achieving Independence: The Challenge for the 21st Century*, NCD made several recommendations to USAID on creating a disability development policy with measurable goals and timelines. In September 1997 USAID issued a policy promoting inclusion of people with disabilities in all development activities.

In December 1998, USAID issued its First Annual Report on the progress of its new policy. The report noted minimal progress and urged the following goals, which were immediately endorsed by then-Administrator J. Brian Atwood:

- every mission will have a specific disability plan by the end of calendar year 1999.
- eighty percent of missions will have at least one contact organization in the disability community.
- there will be an increase in the involvement of people with disabilities in USAID activities as measured by self-reporting and a survey of activities in at least three organizations.
- training on disability and sensitivity to disability will be a part of the regular training program for leaders and for leadership development.
- Bureau of Program and Policy Coordination/Center for Development Information and Evaluation will commission an evaluation of the impact of inclusion of people with disabilities on the overall implementation of at least one of the five USAID strategies.

On December 3, 1999, the new Administrator, J. Brady Anderson, issued a statement affirming his support of the USAID Disability Policy and inclusion of people with disabilities at every level in USAID. A second-year report is being prepared.

NCD commends USAID for initiating the policy of involving people with disabilities in development activities, and for its earnest and ongoing evaluation of its implementation of that policy. NCD reiterates its recommendation to the Department of State and USAID to ensure that all foreign aid and assistance is developed and delivered in a manner that ensures full participation and accessibility by all people with disabilities in the geographic region served by the aid or assistance. Latin American organizations serving individuals with disabilities should not be left to recover on their own current budgets when aid to assist victims of Hurricane Mitch was distributed.

4. Organization of American States

The Inter-American Convention for the Elimination of All Forms of Discrimination for Reasons of Disability was adopted by a number of member states at the first plenary session of the Twenty-Ninth Regular Session of the Organization of American States in Guatemala on June 7, 1999. This Convention seeks to set enforceable and achievable standards for the equitable treatment and optimal level of independence and quality of life of persons with disabilities throughout the hemisphere. NCD and other disability community stakeholders reviewed and provided comments on the draft policies and the final Convention. The adopted Convention would enter into force following ratification by six countries and would be in force only in those countries that ratify it. *NCD encourages the Mission to the Organization of American States to advocate that the Convention be fully implemented by each member state. NCD encourages Congress to adopt the Convention.*

All of these recommendations are to respond to the many challenges for persons with disabilities and those not yet disabled that increase with each conflict, each natural disaster, and the course of poverty. Thousands in Central America still suffer from the aftermath of Hurricane Mitch and continuing heavy rains. The extent of devastation caused by the civil war in Kosovo and the war in Chechnya is still unknown. And the AIDS pandemic is changing the face of our world.

CONCLUSION

This report reflects the large and small steps taken by America in the last year of the 20th century to ensure that people with disabilities enjoy the full benefits of American citizenship and prosperity. Within these pages are the incremental events, legal actions, legislative victories and defeats, and policy actions for one year out of more than three decades of such activities that make up the movement for civil and human rights and access to society for individuals with disabilities. It began as a grassroots movement of small groups of individuals establishing their concerns and demands for opportunities and human rights to the greater society. That movement has taken on the sophistication of maneuvering in the halls of legislatures and policymakers at the local, state, and federal levels, but much of the energy, vision, and force remains at the grassroots.

The year 2000 brings celebration. It will mark the 25th anniversary of the passage of legislation guaranteeing free and appropriate public education for children with disabilities now embodied in the Individuals with Disabilities Education Act (IDEA). Also, we will mark the first decade since the enactment of the Americans with Disabilities Act (ADA). We have much to celebrate.

These milestones present an opportunity to reinvigorate federal enforcement of disability rights laws so that more Americans with disabilities and their families can realize the dream of equal access to full participation in American society. We must commit the leadership and resources to enforce our civil and human rights laws to make sure that protections in law are protections in fact. NCD will do so by releasing two more parts of their "Unequal Under the Law" series on enforcement of IDEA and the ADA.

At the same time, we should heed the words of Disabled Peoples' International during the International Day of Disabled Persons at the United Nations on December 3rd:

As we approach the new millennium, we must reflect on the issues affecting the lives of one of the largest groups among the poorest, and the serious conditions in which the majority of people with disabilities still live, even in the most industrialized countries today. We have raised awareness about poverty and disability, lack of health care services, lack of education and vocational training, and many other issues that are the consequences of lack of accessibility and social integration. We have raised awareness about human rights violations and the atrocities committed to persons with disabilities in areas of civil unrest.

The year 2000 must mark the time America and the world come to full stride in the race to provide access to opportunities to individuals with disabilities to take part in their communities on an equal level with others. No longer will we tolerate the immense economic and social costs of keeping 54 million Americans, and a significant portion of the world population, at the margins of society. No longer will we tolerate segregated education for individuals with disabilities or anything less than the highest quality education for all children

This coming year we admit the reality that access to jobs by workers or potential workers with disabilities is not happening. The Federal Government and states must implement a groundswell of new education and habilitation/rehabilitation strategies to ensure that the overwhelming majority of the next generation of individuals with disabilities participates in the prosperity of work, and not mere survival on income maintenance programs.

This coming year we provide a continuum of long-term care services to ensure that nursing home or other institutional care is not the "default solution." Access and adequate support to live where they choose is fundamental to individuals with disabilities to exercise their civil, political, social, religious, and cultural rights in society.

This coming year we ensure that the new world economy, an economy already defined by technology, is also defined as an economy with the ability to unlock the potential of individuals with disabilities. Worldwide accessible technology is imperative.

Let this new millennium mark a realignment of commitment from government, private sectors, and society to support the enormous energy of the grassroots movement for civil and human rights and access to society for individuals with disabilities.

APPENDIX

MISSION OF THE NATIONAL COUNCIL ON DISABILITY

Overview and Purpose

NCD is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.

- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, Congress, the secretary of education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.

- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.

- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).

- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.

- Making recommendations to the director of the National Institute on Disability and

Rehabilitation Research on ways to improve research, service, administration, and the collection,

- dissemination, and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.

Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report.*

International

In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

While many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and

persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was NCD that originally proposed what eventually became the ADA. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that those persons with disabilities who are members of minority groups fully participate in society.

Statutory History

NCD was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.

Endnotes

1. The three questions on disability were evolved from a concerted interagency effort of the Federal Government. Quoted from Kathryn J. Maney, Partnership and Stakeholders Branch, Census 2000, U.S. Census Bureau, U.S. Department of Commerce.

2 Cited in the Presidential Task Force on Employment of Adults with Disabilities, ***Re-Charting the Course: If Not Now, When?*** Printed November 15, 1999, and prepared with the assistance of Health Systems Research, Inc. A copy of this report can be found at www.dol.gov.

3. See the National Council on Disability report, ***National Disability Policy: A Progress Report*** to the 105th Congress, February 16, 1999. This report can be found at NCD's website www.ncd.gov.

4. A paper prepared by the Georgetown Federal Legislation Clinic for the Consortium for Citizens with Disabilities.

The paper is titled ***Principles for Health Information Privacy Legislation*** [no date provided]. For more information, contact Jeff Crowley, NAPWA, at 202-898-0414.

5. See Singer, Peter, ***Practical Ethics*** [2nd edition]. Cambridge University Press, Cambridge, England, 1998, and also the fact sheet from the Center on Disability and Health by Bob Griss, Washington, DC, 1999; and the ***New Yorker*** magazine article titled "The Dangerous Philosopher" by Michael Specter, September 6, 1999.

6. The executive summary of ***Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation*** can be found at NCD's website www.ncd.gov/newsroom/publications/lift_report.

7. For more information, a fact sheet, and questions and answers about the Work Incentives Improvement Act of 1999, go to the Social Security Administration's website at www.ssa.gov.

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